

**Factors affecting delay in early diagnosis and initiation of  
treatment for tuberculosis in Vellore district-Tamil Nadu.**

**A dissertation submitted in partial fulfillment of the requirement**

**of**

**The Tamil Nadu Dr. M. G. R. Medical University**

**For the M. D. Branch XV (Community Medicine)**

**Examination to be held in April 2016**

# CERTIFICATE

This is to certify that “**Factors affecting delay in early diagnosis and initiation of treatment for tuberculosis in Vellore district-Tamil Nadu**” is a bonafide work of Dr.Siddabathula Harika, in partial fulfillment of the requirements for the M.D. Community Medicine examination (Branch XV) of the Tamil Nadu DR M.G.R. Medical University to be held in 2016.

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**1.Introduction**

Tuberculosis is a widespread disease. The disease is fatal in many cases as it is caused by different strains of Mycobacterium tuberculosis. Tuberculosis bacilli attacks lungs, however other parts of the body are not exempted. The disease is contagious and spreads through the air.Tuberculosis spreads through contact with the person who is infected, as they cough or sneeze. Most of them are asymptomatic, also called as latent TB infection(1). In 90% of cases the tuberculosis bacilli attacks lungs. When lungs are affected the symptoms includes prolonged cough with sputum production, 25% of the people may remain asymptomatic.A vaccine against TB is available nearly for a century. Effective treatment for TB is available nearly for 60 years. Yet the disease is close to its highest levels ever seen. It remains a potentially fatal disease still.

Every year 6 million people die of HIV/AIDS, TB and malaria. Among all these

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I dedicate my study to all my patients who helped me understand life better.

## Acronyms

AIDS	Acquired immune deficiency syndrome
AOR	Adjusted Odds Ratio
CHAD	Community Health and Development
CMI	Cell Mediated Immunity
CI	Confidence Interval
DOTS	Direct Observed Treatment Short course
HIV	Human immune virus
NGO	Non-Governmental Organization
NTP	National Tuberculosis Program
RNTCP	Revised National Tuberculosis Program
SD	Standard Deviation
SPSS	Statistical Package for Social Sciences
TB	Tuberculosis
TU	Tuberculosis Unit
W.H.O	World Health Organization

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## **ABSTRACT**

TITLE OF THE STUDY: Factors affecting delay in early diagnosis and initiation of treatment for tuberculosis in Vellore district-Tamil Nadu.

DEPARTMENT: Community Health And Development

NAME OF THE CANDIDATE: Dr. Siddabathula Harika

DEGREE AND SUBJECT: MD; Community Medicine

NAME OF THE GUIDE: Dr. Jasmin Helan

### Objectives:

Tuberculosis is the leading killer, affecting adults in the developing countries.

Estimates suggest that an untreated, smear positive patient can infect, on an average 10 contacts annually and more than 20 during the course of the disease. A delay in TB diagnosis may lead to more advanced disease state at presentation. Late-stage presentation may contribute to a poor response to treatment, resulting in more severe morbidity while increasing the risk of transmission. It is important to identify the causes of such delays to efficiently take measures to achieve target of case detection and elimination.

### Methods:

The present study is a cross sectional study. The main objectives of this study were to find the average delay in diagnosis/treatment in TB and to identify the determinants of delay in treatment seeking including perceived stigma. The study is done among the newly diagnosed sputum positive tuberculosis patients who were registered in the Tuberculosis Unit run by the Community Health Department of Christian Medical College, Vellore. After obtaining informed consent, study participants were

interviewed by the investigator using a structured questionnaire. To study the level of perceived stigma related to Tuberculosis, 100 people from rural area were interviewed. Data was entered using Epidata and analysis was done using SPSS.

#### Results with conclusions:

We included 95 patients with TB and 100 from general population to know stigma in community. The mean total delay from the onset of disease to initiation of treatment was 104.8 days. The patient delay, health system delay, centre delay and treatment delay were 38.5, 99.3, 60.8 and 2 days respectively. The median total delay, patient delay, health system delay, centre delay and treatment delay were 91, 20, 90, 16, and 2 days respectively.

Participants with TB were found to have more perception of stigma ( $p < 0.001$ , OR=7.19). Among the general population, participants with good knowledge had more perception of stigma (OR=2.40,  $P=0.003$ ). Other factors that were independently associated with delay were low SES ( $P=0.03$ , OR=2.77) and more number of health centres visited ( $p < 0.001$ , OR= 5.682).

In order to minimize the level of perceived stigma related to TB and to improve early health seeking, awareness should be created in the general population regarding the transmission of TB. Awareness need to be created on complications of not treating early and the high cure rate with early treatment and the type of health facility where screening can be done.

From this study it is imperative that the local medical practitioners should be motivated to screen for Tuberculosis at the first onset of symptoms. Frequent continuing medical education sessions may improve case finding and minimize the delay. As most people choose to go to private practitioners for the chest symptom, more diagnostic facility to test sputum should be made available.

# Introduction

Tuberculosis is a widespread disease. The disease is fatal in many cases as it is caused by different strains of *Mycobacterium tuberculosis*. Tuberculosis bacilli attacks lungs, however other parts of the body are not exempted. The disease is contagious and spreads through the air. Tuberculosis spreads through contact with the person who is infected, as they cough or sneeze. Most of them are asymptomatic, also called as latent TB infection(1). In 90% of cases the tuberculosis bacilli attacks lungs. When lungs are affected the symptoms includes prolonged cough with sputum production, 25% of the people may remain asymptomatic. A vaccine against TB is available nearly for a century. Effective treatment for TB is available nearly for 60 years. Yet the disease is close to its highest levels ever seen. It remains a potentially fatal disease still.

Every year 6 million people die of HIV/AIDS, TB and malaria. Among all these deaths tuberculosis attributes to 2 million deaths. TB is a pandemic; half of all reported cases are in 6 Asian countries – Bangladesh, China, India, Indonesia, Philippines and Pakistan. But a highest rate of per capita cases are from African countries i.e. it includes one-fourth of all the TB case. Tuberculosis is the leading killer, affecting adults in the developing countries. It was the seventh most leading cause of morbidity in 1990. The trend is expected to continue till 2020. In 2001; 1.86 billion persons were infected with tuberculosis according to WHO estimates. Statistics shows that each year 8.74 million people may get infected with tuberculosis and of these nearly 2 million die of the disease(2).

As per the statistics it comes to light that someone somewhere gets affected and dies of TB every 10 seconds. Hence in 1993, TB is declared as global emergency by the WHO. According to the estimates it showed that 37 million people were saved between 2000 to 2013 with effective diagnosis and treatment. However in 2013, it was estimated that those affected with TB attributed to 9 million and among those who died of the disease were 1.5million; of which 360,000 were HIV-positive.

India has the highest burden of TB. Global incidence of TB is 9 million cases, out of which 2.1 million cases of TB incidence is reported in India according to WHO estimates in 2013.

The estimated figure for prevalence is 2.6 million as per 2013 WHO statistics(3).TB was declared as a notifiable disease in 2012, which means with immediate effect all private doctors, caregivers and clinics who involved in treating a TB patient should report every case of TB to the government(4). India and China alone contributes to 35 % of cases reported in 2013. According to Global tuberculosis report-2014 published by WHO, 6.1 million TB cases were reported in 2013.Of the reported, 5.7 million people were newly diagnosed and 0.4 million were already on treatment(3). The reasons proposed for rampant increase in disease within the developing world are population explosion, inadequate coverage by control programs, poor cure rates, interaction of HIV with TB(5).as 90% of the infection is symptomatic ,some develop infection before their immune system could get activated. The infection usually progresses within weeks. 25% of the populations stay as carriers or asymptomatic to the infection, of which those who develop latent infection with no treatment comes to

5-10%. It affects those whose immune system is weak. People who are at high risk for developing TB fall into two categories

- a. Persons recently infected with TB.
- b. Persons with conditions that weaken the immune system which facilitate the growth of the TB bacteria(6).

The efforts to combat TB were severely affected for stigma being one of the reason(7). There is vast literature available to understand the factors related or affecting delay in the health seeking behaviour which reflects on early diagnosis and initiation of the treatment in TB patients(8). Apart from socio economic status, knowledge about TB, smoking and other personal characteristics; psychosocial factors also play an important role in the diagnosis of TB(9). The psychosocial factors include stigma in the case TB, which may cause rejection, shame, blame, exclusion from those of healthy individuals(10). There is a great evidence from various studies which suggest that stigma associated with TB could be a reason in delay in seeking health care in TB patients(11).one of the factor highlighted from other studies was many of the patients had the fear that their disease would be labelled as related to AIDS(12). The present study may unfold the scenario in the rural part of Tamil Nadu, Vellore which aids to understand various reasons of delay including stigma in early diagnosis of TB and further initiation of treatment in newly diagnosed sputum positive patients.



## **Justification**

Tuberculosis (TB) is a public health threat globally. The disease causing organism is ubiquitous and is widespread. According to WHO report, an estimated 9.0 million people had TB disease in 2013 and 1.5 million people deaths due to TB were reported(13).

The World Health Organization's (WHO's) under Direct Observed Therapy-Short course (DOTS) strategy; to increase TB success emphasizes on passive case finding. This leaves onus on the patient to approach health facility, making the patient vulnerable to delay in seeking care for their symptoms. This delay may further increase transmission of TB in the community. TB transmission most often occurs between the onset of cough and also after a few weeks after the initiation of treatment. According to estimates an untreated, smear positive patient can infect, on an average of 10 contacts annually and more than 20 during the course of the disease(14).

Notoriously the delay may cause the disease to progress to an advanced stage at presentation. With increased bacillary and presentation after a longer period of delay may contribute to poor response to treatment. This further result in increase in morbidity and also will increase the risk of transmission. The proportion of contacts found to be infected at the time of diagnosis of a smear-positive index case is around 30%–40% (15).

The increase in severe morbidity of an undiagnosed or late diagnosed TB signifies the importance to identify various causes of delay. This aids in taking active measure to achieve target of case detection and elimination. Recent studies done in high-burden TB countries reveals that improving case finding may save 10 times as many lives saved by as DOTS alone(16).

Though there are numerous factors which contribute to delay either due to system or by the patient, in order to improve case finding under RNTCP; it is important to identify and address these factors. Patient's demographic profile, social economic status, and accessibility of the healthcare facilities, availability of competent staff and diagnostic equipment determine passive case finding(17).

These similar factors are identified to be the reasons for delay in many countries. Such delay may occur at the level of the patient (patient delay) or at the level of the health system (system delay) (5-8).

Poverty is one major reason for not seeking proper treatment among both men and women (10). However, decision to go for treatment outside home had been a limiting factor for women compared to men (6). Out-of-pocket expenditure on multiple consultations with local practitioners before diagnosis, lack of money for transport also contributes to delay in proper diagnosis (11).

Stigma, attached to TB, as shown in many studies seems to be a main reason for patient delay. Study in Pakistan showed that majority (85%) of patients felt ashamed to disclose the disease (6). TB and HIV co-infection has also affected the stigma (12). A multi-country study showed that stigma attached to TB is much

more in India than other countries (13). Though there are many studies available from different countries, there is no study from this area assessing the delay, out-of-pocket expenditure prior to diagnosis and the level of perceived stigma. Various studies have demonstrated increased level of perceived stigma among people with tuberculosis. There is lack of information on community's perception towards stigma related to TB. This study attempts to address these issues (13).

### **3. Aims and objectives:**

#### **3.1 Aim:**

The aim of this study is to find out the factors affecting delay in early diagnosis and initiation of treatment for tuberculosis among newly diagnosed sputum positive tuberculosis patients registering in CHAD Tuberculosis Unit (TU) during the period from November 2014 to May 2015.

#### **3.2 Objectives:**

- 1) To study the delay in diagnosis and initiation of treatment in tuberculosis
- 2) To study the determinants of delay in diagnosis and initiation of treatment in tuberculosis
- 3) To compare the knowledge and perceived stigma towards tuberculosis among people with tuberculosis and among the people without tuberculosis.

## **4. Literature review**

Tuberculosis is a major global health problem. It is caused by *Mycobacterium tuberculosis*. It is second leading cause of death worldwide; among the infectious diseases after human immune deficiency virus (HIV). Human beings are its natural reservoir of host. Due to its ability to establish latent infection, it spread to one third of the population worldwide. According to the WHO report of 2013 is estimated that new TB cases accounts to 9 million and TB deaths up to 1.5 million(13).

### **4.1 Pathogenesis of tuberculosis**

#### **4.1.1 Microbiology:**

*M.tuberculosis* belongs to the genus *Mycobacterium*. Tuberculosis (TB) is defined as a disease caused by members of the *M.tuberculosis* complex. It includes the tubercle bacillus (*M. tuberculosis*), *M. bovis*, *M. africanum*, *M. microti*, *M. canetti*, *M. caprae*, and *M. pinnipedii*(18).

TB affects lungs in 85% of cases. Other sites include lymph nodes, genitourinary tract, bones and joints, intestine, skin.

#### **4.1.2 Characteristics of *Mycobacterium tuberculosis*:**

As shown in the figure 4.1, it is a rod shaped bacteria of 0.2 to 0.5 microns (6).

Its cell wall is composed of mycolic acid which stains it acid fast; an acid fast bacilli. It resists acid or alcohol for decolourisation. It is an aerobic bacteria and motile, which multiplies slowly. It has the capacity to remain dormant for decades (6).

Figure 4.1- TB bacilli



Source: internet [www.cdc.org](http://www.cdc.org)

### **4.1.3 NATURAL HISTORY OF THE DISEASE**

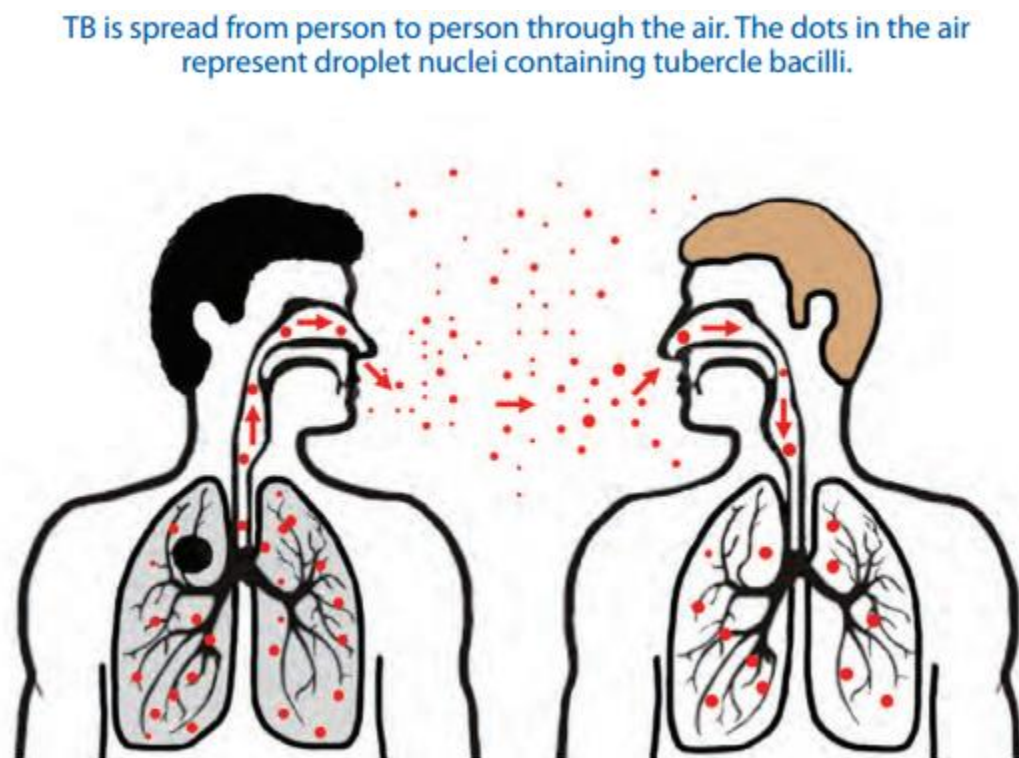
The aerosol droplets containing *Mycobacterium tuberculosis* when inhaled causes deposition in the lungs and leads to one of the possible outcomes. The outcomes may include either immediate clearance of the organism or primary disease (immediate onset of active disease), latent infection, reactivation disease (onset of active disease many years following a period of latent infection) (19).

#### 4.1.4 Primary disease:

Approximately 5 to 10% of the individuals of all the exposed will develop active disease. Among these half of them will develop TB in first two to three years following infection.

The droplets size (5 to 10 microns) is small enough to reach alveoli; the tubercle bacilli are carried in these small droplets to reach the lung. When it comes to multiplication of tubercle bacilli the innate immune system stands as a failure to eliminate the infection. The bacilli proliferate in the alveolar macrophages and further migrate from lungs to other tissue.

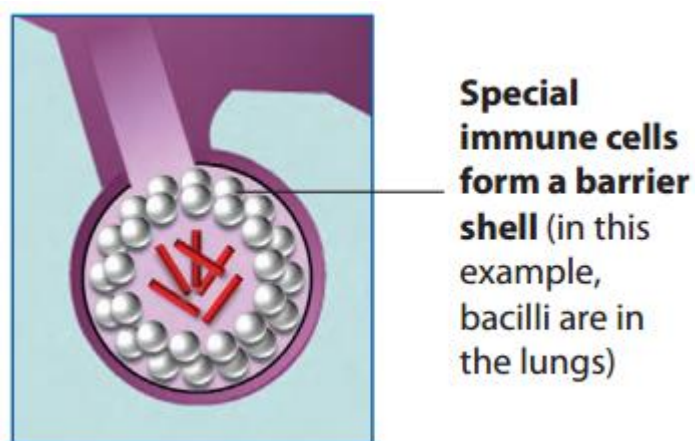
Figure 4.2-droplet transmission of TB



Source: internet [www.cdc.org](http://www.cdc.org)

In the lungs the macrophages produce cytokines and chemokines. These cytokines and chemokines attract phagocytic cells, monocytes, alveolar macrophages, neutrophils. This antigen antibody complex eventually form a nodular granulomatous structure called tubercle

Figure 4.3 pathogenesis of Mycobacterium tuberculosis

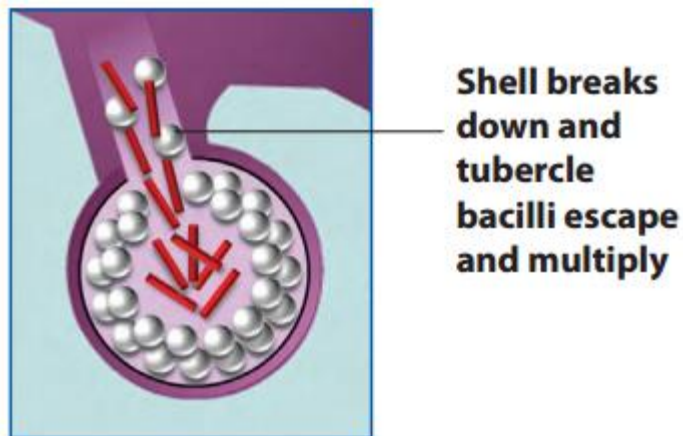


Source: internet [www.cdc.org](http://www.cdc.org)

The tubercle enlarges and bacilli drain into local lymph nodes causing lymphadenopathy. This lymphadenopathy is the characteristic manifestation of primary TB. The lesion thus caused by multiplication of bacilli and further spread to lymphatic system causing lymph node enlargement is called Ghon`s complex.



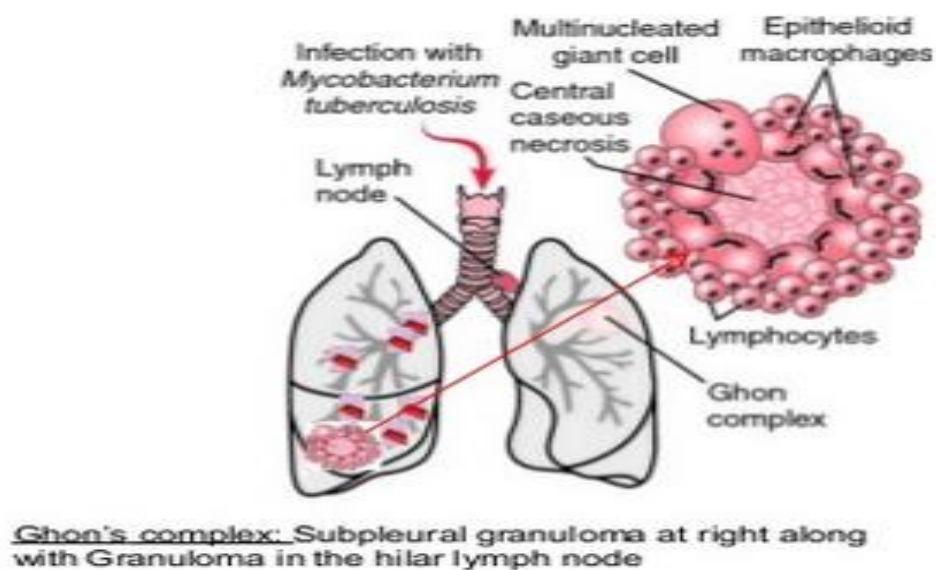
Figure 4.4-Pathogenesis of *Mycobacterium tuberculosis*



Source: internet [www.cdc.org](http://www.cdc.org)

Among those exposed to infective individuals, in nearly 90%, bacilli continue to proliferate for a period of 2 to 10 weeks following infection until an effective cell mediated immune (CMI) response develops. Progressive destruction of the lung occurs due to poor CMI response.

Figure 4.5-Ghon's complex



Source: internet [www.CDC.org](http://www.CDC.org)

If untreated, death ensues in up to 80 % of the cases and the survivors may develop chronic disease or recover. Complete spontaneous eradication of bacilli is rare(20).

#### **4.1.5 Reactivation disease:**

Proliferation of the latent bacteria causes reactivation TB. It occurs in 5 to 10 % of cases during their life time (12).

Immunosuppressive conditions associated with reactivation TB include HIV infection and AIDS, end-stage renal disease, diabetes mellitus, malignant lymphoma, corticosteroid use, inhibitors of TNF-alpha and its receptor, diminution in cell-mediated immunity associated with age, Cigarette smoking(21)(22)(23).

### **4.2Burden of TB:**

#### **4.2.1 Global scenario:**

Deaths due to TB shows 1.5 million, majority of the deaths (1.1million) were HIV-negative people and the rest were (0.4 million) HIV –positive people. In 1990 it was the seventh most leading cause of morbidity. The trend is expected to continue till 2020.In 2001; 1.86 billion persons were infected with tuberculosis according to WHO estimates. statistics shows that each year 8.74 million people may get infected with tuberculosis and of these nearly 2 million die of the disease(24).

As per the statistics it comes to light that someone somewhere gets affected and dies of TB every 10 seconds. Hence in 1993, TB is declared as global emergency by the WHO. With effective diagnosis and treatment, 37 million people were saved during the years 2000- 2013. Reportedly estimated that over 9 million people were affected by TB and 1.5million died from disease of which 360,000 were HIV-positive (1).Global prevalence of TB infection 32% (year 1999).DOTS (Directly observed treatment short course) strategy was established worldwide as a key intervention to achieve tuberculosis control worldwide in 1995. The targets of this strategy globally are to achieve 70% case detection and 85% cure rates by 2005(25).

#### **4.2.2 Indian scenario:**

The estimated figure for prevalence is 2.6 million as per 2013 WHO statistics(3). TB was declared as a notifiable disease in 2012 May, which means with immediate effect all private doctors, caregivers and clinics who involved in treating a TB patient should report every case of TB to the government(4). India and China alone contributed to 35 % of cases reported in 2013. According to Global tuberculosis report-2014 published by WHO, 6.1 million TB cases were reported in 2013.Of the reported, 5.7 million people were newly diagnosed and 0.4 million were already on treatment(3).

Prevalence of TB per lakh population has reduced from 465 in the year 1990 to 230 in 2012(12).

Mortality per lakh population has reduced from 38 in year 1990 to 22 in 2012 in those with TB. In absolute numbers, morality due to TB has reduced from 3.3 lakhs to 2.7 lakhs annually2012 (26).

DOTS program has successfully treated 84% of the registered smear positive cases but could detect only 28% of the estimated tuberculosis cases in the world(27). The key elements of the TB control program are early diagnosis and prompt effective therapy.

Delay in diagnosis will eventually result in increased infectivity of the community. It is estimated that an untreated patient of smear positive tuberculosis has the potential to infection an average 10 contacts annually and over 20 during the natural history of the disease until death(14).

Smear positive cases have high infectivity. In many countries the ministries of health has increased the DOTS coverage since 1990`s.However this increased coverage is not coupled with effective parallel case detection. Coverage is however crucial, but not the only factor for timely access to health services. Studies show that access to treatment is hindered by many factors influencing delay in the treatment in TB patients. Several factors influence delay in diagnosis and start of treatment, which includes individual perception of disease, distance between patient's residence and health services and expertise of the health personnel (5, 6, and 8).

Delay in diagnosis may lead to more extensive disease and high mortality. Delay consequently adds to period of high infectivity in the community (14).

With the advent of RNTCP Program, early diagnosis and prompt effective therapy is at its speed and the treatment centers are decentralized to stick to the policy at its best (14).

Currently detection of TB is done by passive case finding where the patient approaches the health facility. At the health facility with high clinical suspicion and

laboratory confirmation the disease is diagnosed. This major step requires expertise and competency of the health care personnel at the clinical assessment as well as the type of diagnostics available and skills of the laboratory personnel. In this complex continuum, anything can go wrong at any part of the chain that is involved in diagnosing the patient, and the disease remains undetected. This further adds to delay in initiation of treatment and leads to further progression and transmission of the disease with high infectivity and flared up transmission. Consequently increasing the morbidity and mortality as well as transmission(28).

### **4.3 Risk factors for transmission:**

The people who are at risk to contract the infection include close contacts with TB, those living in crowded conditions, conditions like HIV which weaken the immune system, conditions where people require treatment with immunosuppressant like corticosteroids, chemotherapy, or tumor necrosis factor (TNF) inhibitors, those that is young or old-because their immune system tends to be weaker than those of healthy adults (29).

Also in poor health or poor diet-such as drug misuse, alcohol misuse, or homelessness and inhabitants or immigrants who have spent time in country with high levels of TB(29).

The density of population, size of family, crowded localities or living condition, poor ventilation favour higher rate of infection and more disease(30).

Indiscriminate coughing and spitting by those with the disease will increase the bacterial load and pose a threat of vicious cycle in the family. Covering mouth and while coughing is an effective method as well as good ventilation may reduce the risk of transmission of the disease. Untreated or partially family member is the source of infection in many cases(30).

TB is serious obstacle to sustainable development. TB and poverty are interrelated. Burden of the disease on the family increases the expenses for treatment as they approach multiple health facilities before the diagnosis, though the DOTS are free of cost. Thereby push a family into debts and exacerbating the existing poverty. It decreases a person's work capacity, forming a vicious circle. 80% of the patients are in economically productive age group(15-44years), the economic and social cost to them is huge(17).

#### **4.4 TB and its economic impact:**

TB costs Rs. 12000 crore annually to India. Approximately 300,000 school drop outs due to parents TB are other non-disease costs of TB. The cost to patient as he approaches different health facilities before reaching the diagnosis and successful treatment averages US\$ 100-150, more than half of income of daily wage laborer. On an average 3 month of work time is lost if an adult has TB; resulting in loss of 20-30% of annual household income. If a patient dies from disease an average of 15 years of income is lost(3).

#### **4.4.1 Indirect cost to society:**

US\$3 billion per year, direct cost US\$ 300 million. 100 million productive workdays per year are lost due to illness alone. India loses more than 13 billion productive days due to TB deaths. More than 100000 women are rejected by their families on account of TB.

The patient with TB, with sputum smears positive acts as a reservoir as well as source of infection for tuberculosis. Disease burden of bacillary cases in India is over 3.8 million and every year we detect 1 million smear positive cases(30).

#### **4.5 Mortality from tuberculosis in India:**

With advent of DOTS, mortality rate has declined to 23 per 100000 in 2010 from a rate of 42 per 100000 in 1990, thus reducing the mortality rate by 55%. However in sputum positive cases mortality has decreased 7-fold (from 29% to 4%) (17).

TB patient with HIV infection have more chances of deaths (14% against less than 4% in HIV negative TB cases and development of multi drug resistant TB.

Under RNTCP diagnosis and treatment of TB is free of cost. Under RNTCP diagnosis and treatment of TB is free of cost.(31) DOTS increased coverage in several health facilities in several countries since 1990s, however there are still gaps in the diagnosis as well as initiation of treatment.

Multiple factors were identified to contribute to the delay in both diagnosis as well as initiation of TB treatment. The individual perception of the disease, socio economic

level, stigma, lack of awareness of the disease, severity of the disease, distance between the nearest health facility and the patient's residence are few of the listed factors for delay as shown by various studies. There are challenges involved in identifying the factors involved. Delay may occur at any level, the delay for a patient to reach a health facility is called patient delay, and delay in diagnosis of TB at the health facility is health system delay. Delay in case finding is studied in many countries, in low prevalence countries delay is either attributed to disintegration of the previous TB infrastructure for TB control or the disease is not suspected of TB (19-22).

Longer delays were noticed in high prevalent countries. This delay was either due to patients in approaching health care or physicians delay in diagnosis. Reported determinants of delay include being part of specific patient groups (i.e. women, rural versus urban residents, nationality, etc.) (20), either availability of the health providers or accessibility to health services (20-21).

These studies show the association between delay and an increased economic burden and also mortality attributed to tuberculosis. In order improve quality of RNTCP country-specific determinants of delay must be studied and addressed.

#### **4.6 Knowledge and health seeking behaviour on tuberculosis:**

In a cross-sectional study done in the Ilala District hospital, Tanzania on consecutive patients with pulmonary tuberculosis (TB) symptoms and who attended the clinic for medication; health seeking behaviour of the infected was affected. Over half of the patients (54.3%) said that they openly speak about illness to others, but 36.3% said



that their family and friends became less friendly. Others were discriminated even after starting DOTS. This further delays the control of disease(32).

The commonest contact was another family member. People with poor recall ability masked the history of TB contacts and lack of knowledge of TB status is noticed among study population. (32).

Risk of infection is high among the close contacts(33). The close contacts usually were family members. The transmission of TB generally occurs indoor, where droplet nuclei stay in the air for a long time (4). In a study in Bangkok, Thailand, the prevalence of TB among households contact was 47.08% (34). This confirms the existence of knowledge that TB transmission is associated with environmental factors (32, 33).

A WHO study was done on seven countries of the eastern Mediterranean region on the health seeking behaviour of patients and health system response. The study was conducted during the period of 2003-2004. Among the countries which were included, in Pakistan the study was conducted in DOTS centers. In Iraq it was conducted in respiratory and chest diseases institute and 3 other tuberculosis centers. In Somalia a convenient sample was chosen from accessible centers of DOTS. In other countries nation-wide cross sectional studies were conducted(35).

The age group of the study population is taken as 15 years and above. All newly diagnosed smear positive cases are included in the study with estimated incidence for tuberculosis least reliable sample size calculated was 5053 patients; data collected

using clustered random sampling technique. A positive history of previous exposure to a tuberculosis patient was recorded in 12%–20% of patients in Syrian Arab Republic, Egypt and Yemen, in more than one-third of patients in the Islamic Republic of Iran, almost half of the patients in Somalia. In 93.4% of patients in Pakistan, the main symptom that prompted the patients to seek health care was cough with or without fever(35).

Social isolation and stigmatization were overall manifest in each gender's perception about tuberculosis as an illness. In Iraq, the degree of stigma was high (89.8%) for most tuberculosis patients(38).The main source of information about tuberculosis was friends/relatives (44.6%) as well as other tuberculosis patients (51.9%)(35).

In Pakistan, self-medication (50%), only 25 visited health care provider. However, when the symptoms did not subside then the number increased to 239 patients. On repetition of the symptoms next choice of preference was (33.5%) a traditional healer. During the third time when the symptoms did not subside, but a higher percentage (66.1%) also consulted a health care provider.

Most patients incurred heavy expenditures before the diagnosis of tuberculosis was made. The median expenditure incurred was US\$ 17.1 with a mean of US\$ 18.6 ( $\pm 14.62$ ). In Pakistan (96.3% of cases) visited private clinic with the advent of symptoms.

## **4.7 Reasons for delay in diagnosis from various studies:**

The mean duration of delay between the onset of symptoms and treatment ranged from 46 days in Iraq to 127 in the Islamic Republic of Iran.

Patient delay in the Syrian Arab Republic was significantly associated with inadequate knowledge (AOR-1.07; 95% CI 1.01–1.14), seeking health care from a traditional healer, (AOR 5.66; 95% CI 3.02–10.62), and seeking care from more than one health care provider (AOR 1.20; 95% CI 1.02–1.40). In Yemen the significant risk factors for patient delay were: female sex (AOR 2.03; 95% CI 1.1–3.6) and inadequate knowledge regarding the disease (AOR 1.1; 95% CI 1.04–1.2) for each unit of poor knowledge.

The fatalistic attitude of patients i.e. (60.5%) patients felt that the illness would cure itself. Financial issues (16%) played a crucial role in delay in patients. Other reasons were economic constraint, fear of diagnosis and social isolation (stigma) and perceived poor quality of health services or inadequate staff attitude.

### **4.7.1 Risk factors of health system delay**

The WHO study on seven countries of the eastern Mediterranean region also revealed that older age positive history of chronic pulmonary disease and seeking initial care from the private sector were risk factors for health system delay (AOR 1.001; 95% CI 1.003–1.007, AOR 1.3; 95% CI 1.2–1.5 and AOR 1.2; 95% CI 1.1–1.3 respectively) (32).

In Tanzania, a longer health care system delay was seen when patients, especially in rural areas, consulted traditional healers (36). In Gambia, patients who initially consulted health care providers had a shorter delay compared to patients who initially consulted alternate healers (37). In Nepal longer patient delay in women was contributed to by consultation with traditional healers and more frequent visits to health care providers before final consultation with the NTP (38).

A significant difference was seen in initiation of treatment after diagnosis between private health care providers and tuberculosis centers. When a patient was diagnosed by a tuberculosis centre a median of 2 days and mean of 33 days was seen between diagnosis and initiation of treatment. However when private practitioners diagnosed a case of tuberculosis they took a very long time to initiate treatment (median 10 days; mean 98 days) (32).

Lower income or the long distance to reach the health care providers prompted the patients to either try self-medication (50%) or consult a pharmacy (42.2%) as the first action after symptoms in Pakistan (32).

In Egypt the significant factors were: being illiterate (2.76 fold increased risk); time to reach health facility  $>1/2$  hour and  $>1$  hour (1.73 and 1.75 fold increased risk compared to those  $\leq 1/2$  hours); high crowding index (1.2 fold); and more than one health care provider before diagnosis (2.55 fold increased risk)(32). In most of the

health centers patients were not satisfied with the health care facilities and consulted the alternate methods of treatment providers including homeopaths (32)

The significant risk factors for patient delay that were frequently reported from the studied countries were living in suburbs and rural areas, inadequate knowledge regarding tuberculosis, a high degree of stigma, inadequate satisfaction with care, seeking health care from a non-specialized individual at onset of symptoms, and seeking care from more than one health care provider.

A study from India showed that tuberculosis patients on an average visited 2.5 doctors before reaching the NTP (39). The delay reported from Pakistan was comparable to the rates reported from Viet Nam, i.e. a mean of 69.3 days and median of 44.1 (40).

The mean duration between the onset of symptoms and treatment was 46 days in Iraq, 57 in Egypt, 59.2 in Yemen, 79.5 in Somalia, 80.4 in Syrian Arab Republic, 100 in Pakistan, and 127 in Islamic Republic of Iran. Various mean delay durations were reported from different endemic countries: 60 days from India, 87.5 days from Malaysia, and a median delay of 99 days from Nepal (35-37).

Socio demographic characteristics proved to be significant predictors of delay in almost all countries. Age above 35 years was associated with a 1.01–1.7 fold increased risk per year in Syrian Arab Republic, Islamic Republic of Iran and Iraq. Female gender was associated with an increased risk for delay in Yemen but was

protective in Egypt, prompting patients to seek timely health care. Illiteracy and overcrowding were also significant risk factors in Egypt and Iraq, respectively.

Residence proved to be a significant risk factor for delay in Iraq, Somalia, and Pakistan where living in suburban areas was associated with a 3, 2.2 and 2.5-fold increased risk for delay in treatment, respectively, compared to urban areas(32).

The study done in health facilities in four districts in South India to investigate risk factors for patient and health system delays among new smear-positive tuberculosis patients contain health facilities that served urban, semi-urban and rural populations. At each of the selected health facilities, all new smear-positive pulmonary tuberculosis patients aged 15 years diagnosed during the preceding month and subsequently undergoing treatment were considered eligible for the study. Cases diagnosed only on the basis of X-ray and those with previous history of treatment were excluded.

Among 531 participants, the median patient delay was 20 days, health system delay was 23 days and total delay was 60 days. Among the 29% of patients who delayed seeking care for 1 month, 40% attributed their delay due to lack of awareness about TB. Men delayed seeking care than women (P 0.07). In multivariate analysis, if the patient had initially consulted a government provider (adjusted odds ratio [AOR] 2.2, p value 0.001) the delay was more. Residency at a distance 2 km from a health facility (AOR1.6, P 0.04), and was an alcoholic (AOR 1.6, P 0.04) also caused more than. Health system delay was 7 days among 69% of patients (36).

First consultation with a private provider (AOR 4.0, P 0.001), a shorter duration of cough (AOR 2.6, P 0.001), alcoholism (P 0.04) and patient's residence 2 km from a health facility (AOR 1.8, P 0.02). The total delay resulted largely from a long patient delay when government providers were consulted first and a long health system delay when private providers were consulted first.

Public awareness about chest symptoms and the availability of free diagnostic services should be increased. Government and private physicians should be educated to be aware about the possibility of tuberculosis when examining out-patients.

Effective referrals for smear microscopy should be developed between private and public providers(39).

In conclusion, patient delay is mainly dependent upon the health-seeking behaviour of tuberculosis patients which is mainly determined by their socio demographic characteristics, place of first consultation and degree of stigma felt and knowledge regarding the disease (32).

#### **4.8 Stigma associated with TB:**

In the study done in Zambia TB is reported as a contagious disease in 57% of respondents (36). Of the total respondents 75.6% knew that TB is curable (38).

Many of them wanted to live in isolation (self-discrimination) which may be due to fear of transmitting TB, and avoiding gossip and potential discrimination. This attributes to 42.9% of men and 36.9% of women and they strongly agreed with this idea (41).

A study from Dharan, India also depicted that stigma and treatment outcome and delay in seeking care were associated (42).

High degree of stigma was protective (AOR = 0.64 (0.51–0.82)), in that the high degree of stigma attached to tuberculosis by some patients is presumed to have motivated them to seek health care earlier than others (32).

In Pakistan, 37.9% Of the patients in the study evidently showed that fear of diagnosis is one of the reasons for delay in reaching TB clinics. Stigma attached to the disease is expressed a fear of social isolation if diagnosed with tuberculosis by 18.1% of patients disease. One of the co-authors from the previous study done in Pakistan also documented that stigma has a major role in determining the health-seeking behaviour of patients(43),(44).

The efforts to combat TB were severely affected for stigma being one of the reason(7). There is vast literature available to understand available to understand the factors related or affecting delay in the health seeking behaviour which reflects on early diagnosis and initiation of the treatment in TB patients(8). Apart from socio economic status, knowledge about TB, smoking and other personal characteristics; psychosocial factors also play an important role in the diagnosis of TB(9). The psychosocial factors include stigma in the case TB, which may cause rejection, shame, blame, exclusion from those of healthy individuals(10). There is a great evidence from various studies which suggest that stigma associated with TB could be a reason in delay in seeking health care in TB patients(11).one of the factor highlighted from other studies was many of the patients had the fear that their disease would be labelled as related to AIDS (12).



## **4. Methodology:**

### **5.1 study setting**

#### **Community Health Department and Development Hospital (CHAD):**

The Department of Community Health, Christian Medical College, Vellore, India, has been working in Kaniyambadi and Anaicut Blocks and urban parts of Vellore for the past 50 years. The Community Health and Development (CHAD) Program is run by the Department of Community Health. Along with the government health services, it provides primary health care including maternal and child health services, screening and treatment for communicable and non-communicable diseases. CHAD program along with government runs RNTCP program as a Tuberculosis Unit, Tribal health program and school health program. CHAD program runs mobile clinics offering preventive and curative services in each village every month in Kaniyambadi block, parts of Vellore urban and Tribal area (Jawadhi Hills). These areas have grass root workers at the village level that identifies people with medical problems and also function as DOTS providers. Patients who cannot be treated are referred to the base hospital which offers secondary care services. If tertiary care is needed, patients are further referred to the Christian Medical College and Hospital, where specialty care and advanced laboratory services are available.

CHAD Hospital is situated at the outskirts of Vellore town. It is a 135 bedded secondary care hospital and primary referral centre for its distinct outreach activity in

the rural block of Kaniyambadi. CHAD as a Non-governmental Organisation (NGO) runs TB unit under public private mix scheme in RNTCP. CHAD TB unit caters to Kaniyambadi block, Anaicut block, Alangayam block and a part of urban. In 2003 CHAD was recognized as a nodal centre for south zone for the RNTCP. The TB unit of CHAD coordinates the TB activities nearly 15 peripheral centres including Vellore Government Medical College, Narayani Hospital and primary health centres serving 6,50,00 population.

## **5.2 Study design:**

The present study was a cross-sectional study to understand the factors related to delay in diagnosis and initiation of treatment in newly diagnosed sputum positive tuberculosis patients.

## **5.3 Study participants:**

All new sputum positive patients enrolled in various health facilities under CHAD-TU who were diagnosed during November 2014 to May 2015 were included in the study. Temporary residents were excluded from the study.

For the community study among general population, people above 18 years from Kaniyambadi block were included. Only permanent residences were selected.

## **5.4 Sampling technique:**

As the number of new sputum patients registered every month is around 40 in this TU, all participants who were above 18 years of age and willing to be visited by the investigator within 4 weeks of starting treatment were selected.

To study the community's perspective stigma towards TB, 10 villages were randomly selected from Kaniyambai block and from each of these 10 villages, 10 people were randomly selected (two stage sampling). Total of 100 people from general population were interviewed after getting consent. None of the selected participant refused to participate in this study.

### **5.5 Sample size calculation:**

A multi-centric study by WHO showed that the median time delay was between 44 days to 97 days in different countries. The mean delay in Pakistan was 100.7 days (SD 34.2) (6). Using the formula  $N=4SD^2/d^2$ , (with the SD of 34.2 and a d of 7 days), the estimated desired sample size was 95.

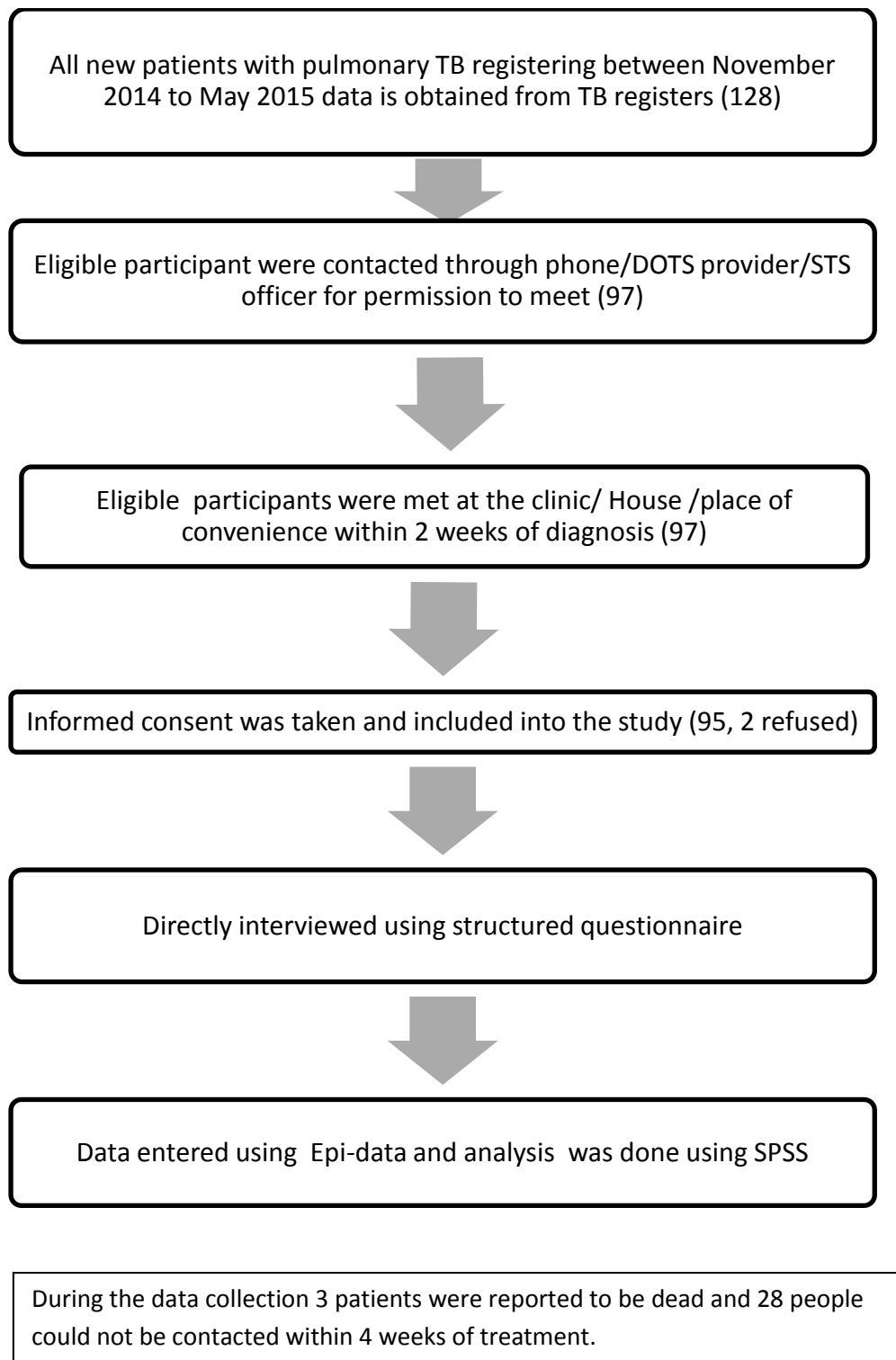
For objective 3, to assess perception of stigma among general population, assuming that 50% will have adequate knowledge on TB, 100 people were included.

### **5.6 Data collection:**

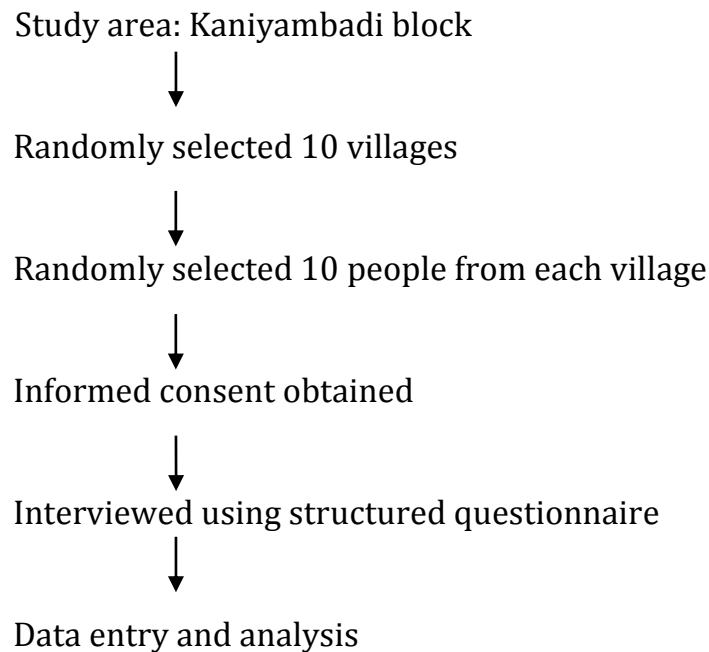
During the study period, 128 patients were registered under the CHAD TU. The details of the study participants were obtained from the TB registers as well as by visiting the government health centres that were under the CHAD-TU. All these patients were contacted through telephone or through the DOTS provider/STS and obtained their oral permission to visit them. Those who gave permission were visited at their residence or at the health centres or any place of their convenience.

The investigator could meet only 97 people as 3 people died within the first 2 weeks and others could not be approached within 4 weeks of starting treatment. As 2 people

did not give consent, only 95 were interviewed. The time limit to interview the participants with TB was taken as 4 weeks in order to minimize the recall bias. The following is the flow chart depicting the method of data collection:



**For objective 3, to study the community's perception regarding stigma towards TB and their awareness:**



### **5.7 Study tools:**

A structured questionnaire was used to collect information. The questionnaire was translated into Tamil (the local language) and back translated into English and pilot tested.

The questionnaire had the following section: socio-demographic details, personal habits like alcohol and smoking, monthly income and debt due to medical treatment, knowledge on symptoms, modes of transmission, method of diagnosis, treatment (duration and follow up) and cure. Participants with TB had another section with questions on their treatment seeking pattern for symptoms suggestive of TB, time gap between the onset of symptom to seeking medical help to diagnosis and initiation of treatment.

Validated TB Stigma Scales developed by Van Rie et al., (2008) was used to measure stigma related to TB. Variables measuring stigma were coded a 4-point Likert scale with the following levels: '0' as strongly disagree, '1' as disagree, '2' as agree, and '3' as strongly agree.

### **5.8 Informed consent:**

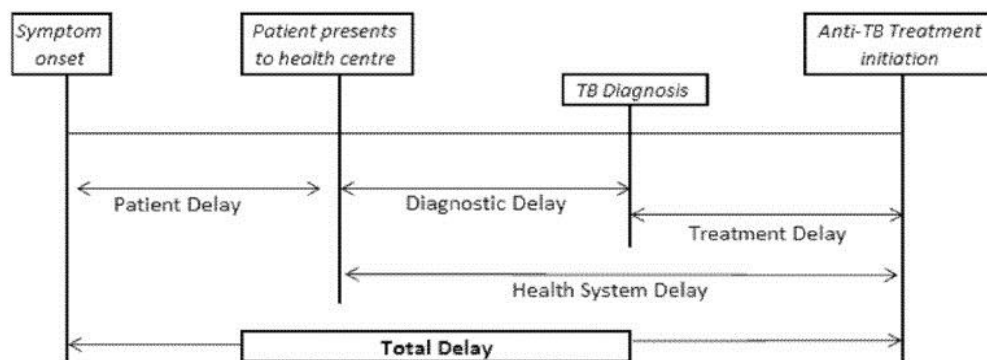
After getting oral consent, the investigator visited the participants and an information sheet (in Tamil) was given to them explaining the purpose of the study, voluntary nature of participation and confidentiality of the concerns and the disease. Participant was verbally explained in their own language and further queries were clarified. Then written consent was taken with their willingness to participate in the present study. The health status of the participants with TB was checked and they were encouraged to be take regular treatment.

### **5.9 Study variables**

The main outcome variables were delay in diagnosis and treatment, knowledge on tuberculosis (symptoms, modes of transmission, treatment and follow up) and perceived stigma related to TB.

**Delay** is the main outcome. Delay can be divided into 2 components – patient delay and health system delay. It can also be divided into diagnostic delay and treatment delay.

**Figure 4.6 Different categories of delay; and their contribution to total delay**



**Stigma:** As measured by the validated scale which was developed by Van Rie et al. in 2008. This scale used a 4-point Likert scale with the codes of ‘0’ for strongly disagree, ‘1’ for disagree, ‘2’ for agree, and ‘3’ for strongly agree. Higher scores were related to higher stigma. This scale has 2 components –The perception of people living with TB about how community perceive or feel about Tuberculosis (Community Tuberculosis Stigma Perception with 11 items), the perception of people living with TB about how Patients perceive or feel about TB (Patients’ Stigma Perception with 12 items).

**Determinants of delay and stigma:** Socio-demographic variables like age, gender, education, occupation, type of house, type of family and economic status of the family.

### **5.10 Data management and analysis:**

Data collected was entered in epidata 3.1 and analysis was done using SPSS 16. Descriptive statistics of the socio-demographic variables was done.

Mean and median delay in days (patient delay and health system delay) was calculated. Using appropriate standards, study group was dichotomized into people with delay and without delay with a cut off of 30 days.

Various determinants of delay were re-coded into binary variables and chi-square and p-value was calculated. Univariate and multivariate analysis was done to see the association between the determinants and the delay.

Knowledge and stigma was given scores and total score was computed. Mean scores was calculated. Knowledge and stigma scores were dichotomized as people with adequate knowledge/ inadequate knowledge and people who have perceived stigma/no stigma.

Association between knowledge and delay, perceived stigma and delay was studied using chi-square tests and regression analysis.

Knowledge between people with TB and without TB was compared using difference in means and by chi-square test (between dichotomized groups). Similarly, perceived stigma between people with TB and without TB was compared using difference in means and by chi-square test (between dichotomized groups).



## 6. Results

The study population consisted of both men and women of 18 years and above age group. The study aimed at assessing the factors related to delay in diagnosis and delay in initiation of treatment in a newly diagnosed sputum positive patient.

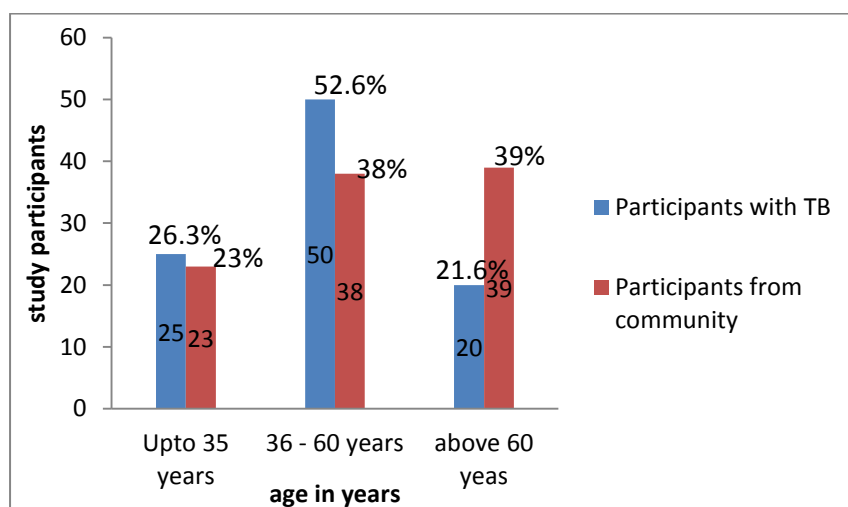
The total number of patients who were interviewed for the study was 95. Among the general population 100 people from Kaniyambadi village were interviewed to assess the stigma related to tuberculosis (TB).

### 6.1 SOCIO DEMOGRAPHIC CHARACTERISTICS:

#### 6.1.1 Age and gender distribution of the patients and general population:

The total number of newly sputum positive TB patients who gave consent was 95. Of these 52.6% (52) of the patients belong to age group 36-60 years of age group, 26.3% (25) were of 18-35 years age group and 21.6% (20) were more than 60 years of age (Figure 6.1).

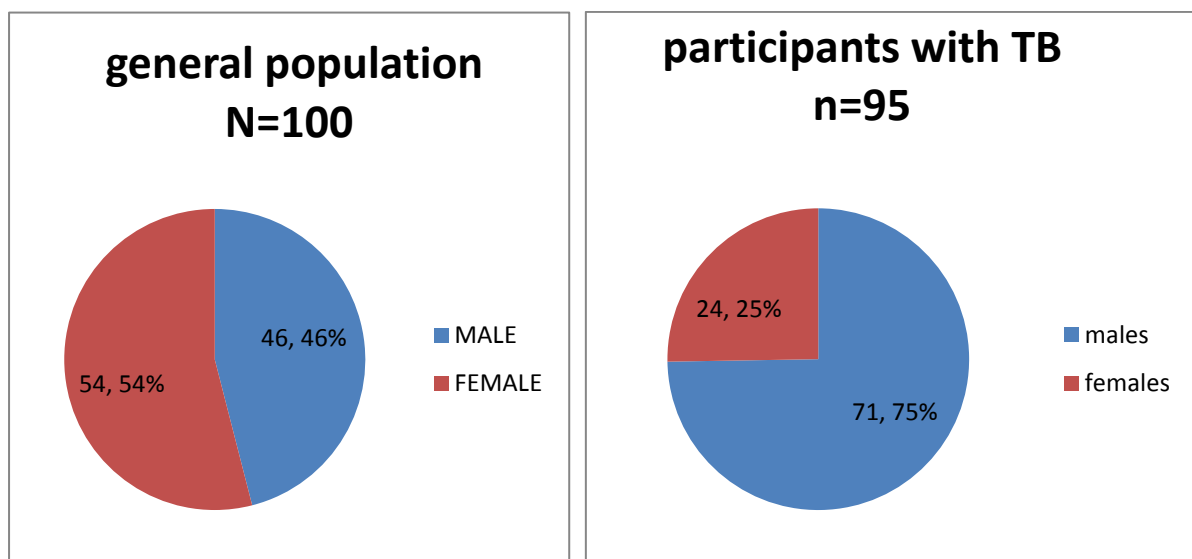
**Figure 6.1** Distribution by age



Among the general population 39% belonged to age group of 60 years and above, 38% belong to 36-60 years and 54% of those interviewed were women (Figure 6.1).

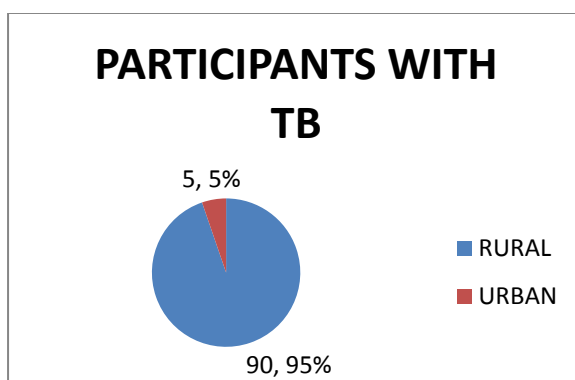
Majority of the study participants were men; 74.7% among participants with Tb and 71.5% in the general community (Figure 6.2).

**Figure 6.2 Distribution by gender**



Among the participants with TB, 94.7% (90) were from rural area and only 5 patient's i.e. 5.3% were from urban area (Figure 6.3). All the study participants among general population are from rural area (Kaniyambadi block)

**Figure 6.3 Distribution by place of residence among participants with TB**

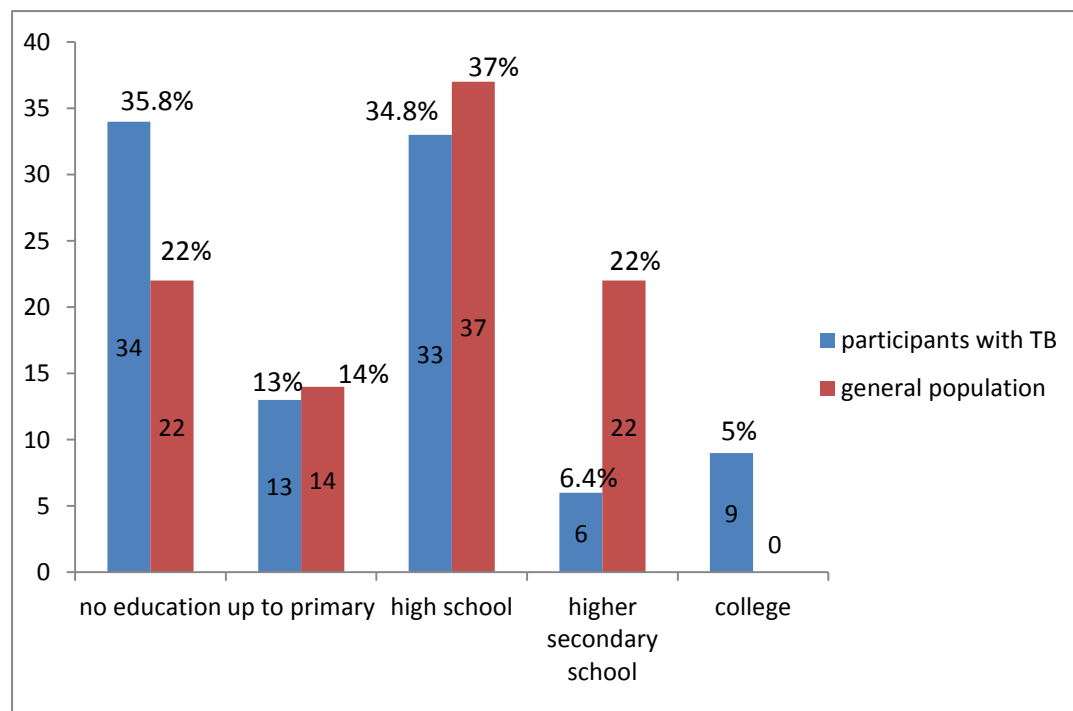


## 6.2 Distribution of educational status of the study population:

Among the study patients 34.8% (33) had education up to high school, where as almost equal proportion of 35.8% (34) were illiterate, only 9.5% (9) of them had education up to college and above (Figure 6.4).

Among general participants only 37% were educated up to high school and 5% has up to college (Figure 6.4).

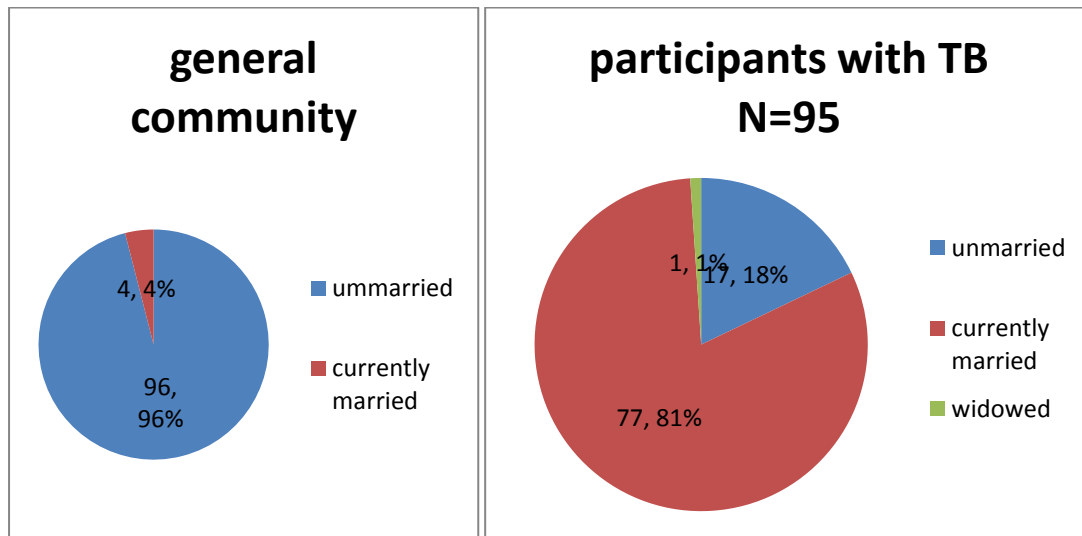
**Figure 6.4 Distribution by educational status of the study population**



## 6.3 Distribution of the study population according to marital status

Among the interviewed 81.1% of the participants with TB and 96% among general population were currently married (Figure 6.5).

**Figure 6.5 Distribution of the study population according to marital status**



#### 6.4 Distribution according to the type of house and number of rooms

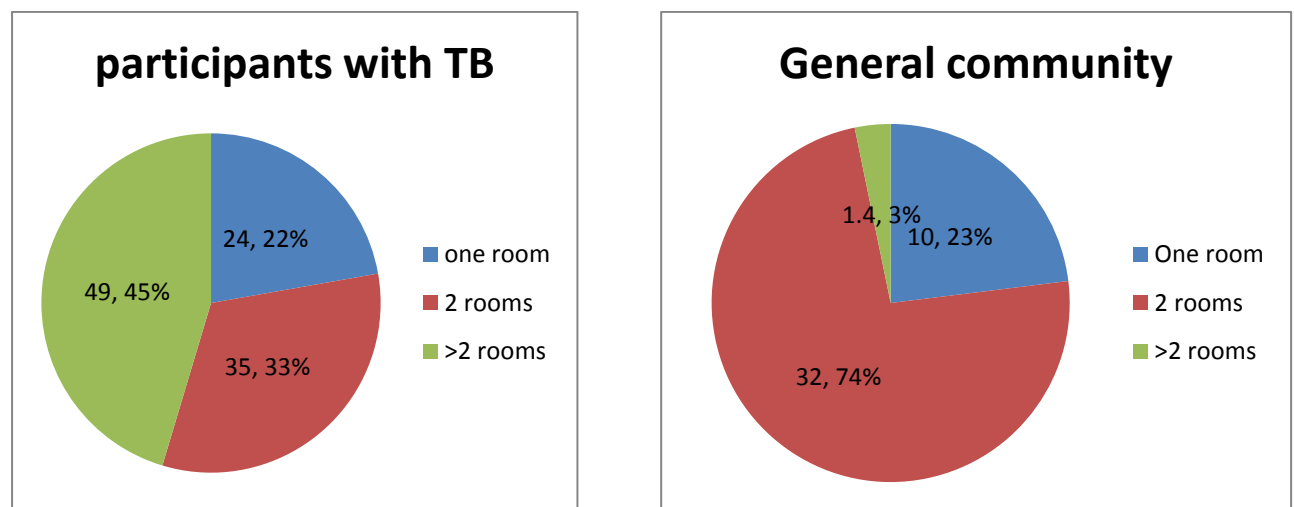
The proportion of the patients who live in terraced houses was 43.2% (41) as compared to 11.6% (11) who lived in huts (Table 6.1). Only one of the patients interviewed was homeless. Among the general population 60% of them lived in terraced houses.

**Table 6.1 Distribution by housing and number of rooms in the house**

HOUSING	Categories	Participants with TB (n=95)		General population (N=100)
		N	%	N& %
Type of house	Hut	11	11.6	4
	Thatched	25	26.3	18
	Tiled	17	17.9	18
	Terraced	41	43.2	60
	Homeless	1	1.1	0

With respect to number of rooms 41% (49) were living in more than 2 roomed houses as compared to 25.3% (24) living in one roomed houses. 58% among general population were living in more than 2 roomed houses (Figure 6.6).

**Figure 6.6 Number of rooms in participants' house**



### **6.5 Distribution of the study group by occupation, socio economic status**

Unskilled and daily wage labourers constituted 29.5% (28) among participants with TB and 14% among general community. The people with regular salaried jobs were 23.1% (22) and 7% respectively among people with TB and others. Unemployed people were 15.8% (15) and 14% among people with TB and others. Among Only 7.4% (7) were house wives alone. Majority of those interviewed among general population were house wives of 35% (Table 6.2).

**Table: 6.2 Distribution of the study group by occupation**

Occupation prior to illness	Participants with TB (n=95)		Participants from community (n=100)
	N	%	N & %
House wife alone	7	7.4	35
Unemployed	15	15.8	14
Unskilled daily wage	28	29.5	16
Farming/business/mason	14	14.7	18
Salaried	22	23.1	7
Retired	5	5.3	10
Students	4	4.2	0

**6.6 Distribution of study population by socio economic status:**

Socio economic status is calculated by Modified Kuppaswamy socio economic scale 2012. Majority (66.3%) of the participants with TB (63) belonged to upper lower class and only 5.3% were from lower class. Similarly 49% of general population interviewed belongs to upper lower class (Table 6.3).

**Table 6.3 Distribution of the study group by socio economic status**

Socioeconomic status	Participants with TB (n=95)		Participants from community (n=100)
	N	%	N & %
Lower	5	5.3	7
Upper lower	63	66.3	49
Lower middle	23	24.2	32
Upper middle	4	4.2	12

## 6.6 Distribution of the participants by monthly income:

As given in Table 6.4, current income of the participant with TB per month is 2776 (95% CI 1974-3598) whereas prior to illness it was 4445 (95% CI 3525-5364).

Current family income per month is 5039 (95% CI 4202-5876) but prior to illness it was Rs.6650 (95% CI 5678-7622). Among the participants without TB monthly income was Rs.3682 (95% CI 2660-4704).

**Table 6.4 Distribution of the participants by monthly income:**

Monthly income	categories	Mean	95%CI
Income of participants with TB	Prior to illness	4445	3525-5364
	Current income	2776	1974-3598
Family income of participants with TB	Prior to illness	6650	5678-7622
	Current income	5039	4202-5876
Income of participants without TB	Current income	3682	2660 – 4704

## 6.2 Personal habits:

### 6.2.1 Distribution of study participants by tobacco smoking:

The proportion of the participants with TB who were current smoking was 45.3% (43) as compared to 9% in the general population (Table 6.5). Among the smoker's i.e. current smokers as well as ex-smokers 38.8% of them consumes 11-20 cigarettes/beedi per day. Duration of smoking as told by the patients was 15-29 years in 32.7% of the smokers and more than 30 years above on 30.7% of them. In the general population majority of them (84%) were never smokers.

**Table 6.5 Distribution of study participants by tobacco smoking**

Smoking	Categories	Participants with TB (n=95)		Participants from community (n=100)
		N	%	N & %
Smoking status	Never	43	42.3	84 (84)
	Current	43	45.3	9 (9)
	Ex-smoker	9	9.5	7 (7)
Daily consumption (number per day) n=52	Upto 10	20	38.5	8 (50.0)
	11-20/	20	38.5	4 (25)
	21-50	7	13.5	3 (18.8)
	>50	5	9.6	1 (6.2)
Duration of smoking n = 52	<15 years	12	23.1	3 (18.8)
	15-29 years	17	32.7	4 (25)
	30 years and more	16	30.7	9 (56.28)

### 6.2.2 Distribution of study participants by their personal habits (alcohol consumption)

The proportion of participants with TB who never consumed alcohol was 3.7% (51), but 38.9% (37) of them were currently consuming alcohol (table 6.6). Among those who ever took alcohol i.e. current alcohol abusers as well as those in the past (44), 31.8% consumed up to 500ml of alcohol per day. 20.5% (9) of them consumed more than 2 litres of alcohol, which was mostly a local brand. Among the alcohol consumers, 29.6% (13) took it at least 2 to 3 times per day. Among the general population, only 4% were current alcohol users (Table 6.6).



**Table 6.6 Distribution of study participants by their alcohol consumption**

Alcohol consumption		Participants TB		General population
		N	%	N % %
Alcohol intake	Never	51	53.7	89
	Current	37	38.9	4
	Past	7	7.4	7
Daily consumption	Upto 500 ml	14	31.8	6 (54.6)
	501 - 1000 ml	13	29.6	3 (27.3)
	>1001 - 2000 ml	8	18.1	2 (18.2)
	>2000 ml	9	20.5	
Frequency of alcohol intake per week	Upto 2 times	12	27.3	6 (54.6)
	3-6 time	13	29.6	1 (9.1)
	Daily	19	43.1	4 (36.4)

In the general population 89% of the interviewees never consumed alcohol, only 11 of them gives history of alcohol abuse either in the past or at the present. Among these 11, 54.6% i.e.6 of them were consuming up to 500ml per day with frequency of 2 to 3 times per week.

### **6.3 History of TB among the study participants**

Among the 95 patients interviewed 4.2% gave previous history of treatment for TB and 16.8% gave family history of TB in the general population 3% had previous history of TB and 3% gave family history of TB.

### **6.4 Symptoms experienced by the patients before they were diagnosed**

Among the newly diagnosed sputum positive patients 93.7% (89) had cough as the symptom, 85.3% (81) also had fever. The proportion of patients who had loss of

weight was 84.2% (80) and loss of appetite was 83.2% (79). Only 22.1% (29) gave history of haemoptysis ( Table 6.7).

**Table 6.7 Symptoms experienced by the patients before diagnosis**

<b>Symptom</b>	<b>N</b>	<b>%</b>
Cough	89	93.7
Fever	81	85.3
Loss of weight	80	84.2
Loss of appetite	79	83.2
Haemoptysis	21	22.1
Chest pain	18	18.9

### **6.5 Symptom for which the treatment is sought**

Majority of them i.e. 40% sought treatment for cough, 28.4% of them sought the treatment as they had fever as their main symptom (Table 6.8).

**Table 6.8 Symptom for which the treatment is sought**

<b>Symptoms</b>	<b>N</b>	<b>%</b>
Cough	38	40
Fever	28	28.4
Loss of weight	5	5.3
Breathlessness	4	4.2
Haemoptysis	5	5.3
Chest pain	8	8.4
Others	8	8.4

### **6.2.6 Health care seeking behaviour with onset of illness**

With the onset of illness 43.2% sought treatment from private hospitals, apart from this 29.5% of them used self-medication. Only 12.6% Of them approached PHC`s with the onset of illness and 1.1% to Government Vellore Medical College, (GVMV) which is a higher government referral centre (Table 6.9).

**Table 6.9 Health care seeking behaviour with onset of illness**

<b>Health facilities</b>	<b>N</b>	<b>%</b>
Self- medication	28	29.5
Traditional medicine	1	1.1
Chemist shop	7	7.4
PHC	12	12.6
GH/CHC	2	2.1
GVMC	1	1.1
CHAD	3	3.2
CMCH	0	0
Private hospital	41	43.2

**6.2.7 Health care facility from where patient first sought treatment**

Private hospital is the first approached health facility by 64.2% of the patients, though 20% of them visited PHC`s for the treatment (Table 6.10).

**Table 6.10 Health care facility from where patient first sought treatment**

<b>Health facility</b>	<b>N</b>	<b>%</b>
Primary Health Centre	19	20
Government Hospital /Community Health Centre	3	3.2
Government Vellore Medical College	3	3.2
CHAD hospital	8	8.4
CMC Hospital	1	1.1
Private hospital	61	64.2

**6.5.1 Health care providers who made initial diagnosis:**

The initial diagnosis of TB was made by GVMC for a proportion of 35.8% and 32.6% of the patients were diagnosed in CHAD (Table 6.11).

**Table 6.11 Health care providers who made initial diagnosis:**

Health facilities	N	%
Primary Health Centre	5	5.3
Government Hospital /Community Health Centre	11	11.6
Government Vellore Medical College	34	35.8
CHAD hospital	31	32.6
CMC Hospital	4	4.2
Private hospital	10	10.5

**6.5.2 Expenditure related to TB care:**

Money spent on approaching health providers for treatment (both direct and in direct costs) was counted. Total cost before diagnosis spent by 38.9% of them was up to Rs.500; only 2 of them spent money of more than Rs.50, 000 before diagnosis (Table 6.12).

**Table 6.12 Expenditure related to TB care**

<b>Total cost before diagnosis (in RS.).</b>	<b>No</b>	<b>%</b>
Upto 500	37	38.9
501-1000	13	13.7
1001-5000	25	26
5001-10000	7	7.4
10001-50000	13	13.8
>50000	2	2.1

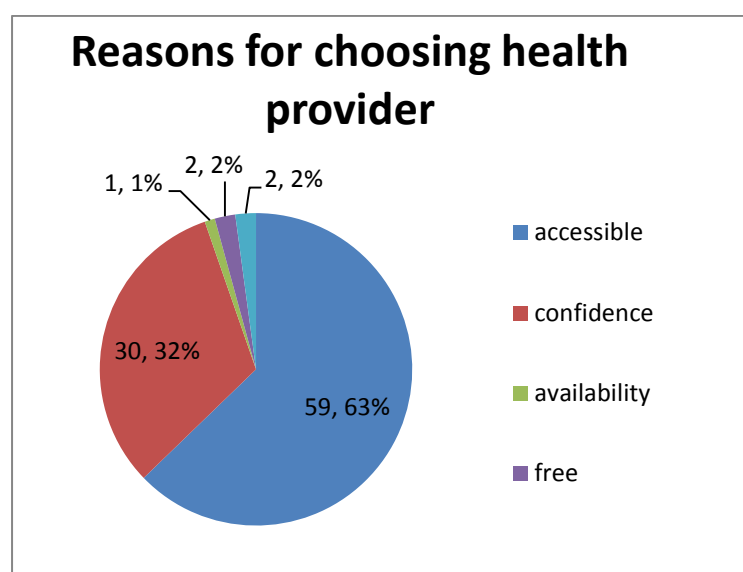
**6.5.3 Debts due to medical expenses (Rs.)**

Out of the interviewed, 58.9% of them did not have any debts due to medical expenses, but 21.1% of them had debts in the range of Rs. 10001 to 50000.

#### 6.5.4 Reasons for choosing the particular provider

Of the interviewed 62.1% said that they choose the particular provider as it was accessible for them; 31% of them has chosen as they had confidence in the particular provider of their choice (Figure 6.7).

**Figure 6.7 Reasons for choosing the particular provider:**



#### 6.5.5 Action/investigations done in the health facility:

Sputum examination is done in 98.9% of the patients interviewed, blood tests were done in 96.8% of them where as 88.4% of them also had chest x-rays taken (Table 6.13)

**Table 6.13 Action/investigations done in the health facility:**

Investigation	N	%
Sputum test	94	98.9
Blood test	92	96.8
X-ray	84	88.4

### **6.5.6 Reasons for not going to CHAD/CMC/GVMC/PHC which are microscopic centres)**

The proportion of patient`s who thought it is not necessary to go to these centres attributed to 47.4% where as 27.4% of them couldn't go as they have no money. Among those who 16 (16.8%) gave others as the reason; 9 of them have immediately approached their regular health provider and waited to be cured of the sickness until they were diagnosed of TB.

### **6.14 Reasons for not going to CHAD/CMC/GVMC/PHC:**

<b>Reasons</b>	<b>N=95</b>	<b>%</b>
Thought not necessary	45	47.4
Too far	2	2.1
Long waiting time/ too busy	3	3.2
Previous bad experience	3	3.2
No money	26	27.4
Others	16	16.8

### **6.5.7 Time delay in diagnosis (number of days)**

The proportion of patients who experienced a delay of 91-180 days was 26.3% and 24.2% of them experienced a delay of 31-90 days in diagnosis of the disease (Table 6.15).

Among those who had delayed 67.4% responded that they considered it as delay.

**Table 6.15 Time delay in diagnosis (number of days)**

<b>Time delay in diagnosis Days</b>	<b>N</b>	<b>%</b>
<b>No delay/&lt;2weeks</b>	10	10.5
<b>15-30</b>	23	24.2
<b>31-90</b>	30	31.6
<b>91-180</b>	25	26.3
<b>&gt;180</b>	7	7.4

### 6.5.8 Reasons by patients for delay

Among the 64(67.4%) who considered it as delay, 53.1% responded that they delayed hoping that symptoms would subside. The proportion of patients who delayed due to economic constraints was 17.2% (11), only 7.8% delayed due to fear of diagnosis (Table 6.16).

**Table 6.16 Reasons by Participants with TB for delay in reaching health centre**

<b>Reasons (n=64)</b>	<b>N</b>	<b>%</b>
Fear of diagnosis	5	7.8
hoped that symptom will subside	34	53.1
Fear of social isolation	1	1.6
Economic constraints	11	17.2
unsatisfied staff attitude	2	3.1
Poor quality of health services	4	6.3
Others	7	10.9

### 6.5.9 Reasons for delay in seeking care in other people in the community who has similar complaints

When asked about the reasons as perceived by the patient among those who had the similar complaints in the community, 51.6% said that they do not have money was the reason for their delay. 28.4% of them said they did not approach as they felt it was not necessary to seek health care (Table 6.17).

**Table 6.17 Reasons for delay in seeking care in other people in the community who has similar complaints**

<b>Reasons</b>	<b>N</b>	<b>%</b>
Not necessary	27	28.4
Too busy	6	6.3
Bad experience	4	4.2
No money	49	51.6
Don't know	9	9.5

#### 6.5.10 Mean patient delay

The time taken by the patient to approach health facility for treatment with the onset of symptom is taken as patient delay. The mean patient delay was 38.5 days with range of 2 days to 540 days with 95% CI of 25.3-51.6 (Table 6.18).

**Table 6.18 patient delay**

<b>Type of delay</b>	<b>Mean</b>	<b>95%CI</b>	<b>Median</b>	<b>min</b>	<b>Max</b>
Patient delay in reaching health facility for diagnosis	<b>38.5</b>	<b>25.3-51.6</b>	<b>20</b>	<b>2</b>	<b>540</b>

#### 6.5.11 Mean health system delay

The time taken from the onset of symptoms to diagnosis of the disease is health system delay. In the present study the mean health system delay in diagnosing was 99.3 days (95% CI 79.5-119.1) and range from 3 to 547 days (Table 6.19).

**Table 6.19 Health system delay**

<b>Type of delay</b>	<b>Mean</b>	<b>95%CI</b>	<b>Median</b>	<b>min</b>	<b>Max</b>
Health system delay in diagnosing	<b>99.3</b>	<b>79.5-119.1</b>	<b>90</b>	<b>3</b>	<b>547</b>

#### 6.5.12 Mean treatment delay

The delay in starting the treatment once the diagnosis is made is considered as treatment delay. The mean treatment delay was 2 days in the present study (95% CI 2.1-3.6) with a maximum delay of 28 days (Table 6.20). This was because one patient couldn't accept the fact that he was attacked with TB; in denial he changed the doctors and only when the symptoms worsened he started the treatment.



**Table 6.20 Treatment delay**

Type of delay	Mean	95%CI	Median	Min	Max
Treatment delay (after diagnosis to initiating treatment)	2	2.1-3.6	2	0	28

**6.5.13 Delay in initiation of treatment on those who are transferred out**

The mean delay in initiation of treatment in patients who were transferred out was 4.5 days with a maximum delay of 60 days with 95% CI of 1.9-7.1 (Table 6.21).

**Table 6.21 Delay in initiation of treatment on those who are transferred out**

Type of delay	Mean	95%CI	Median	min	Max
Among the patients who have been referred out, delay in initiating treatment	4.5	1.9-7.1	2	0	60

**6.5.14 Mean Centre delay**

The delay in diagnosis after the visit to the first health care provider was centre delay (first health centre to final health centre). The mean centre delay was 60.8 days (Table 6.22) with maximum delay of 358 days (95% CI 42.3-78.8).

**Table 6.22 Centre of delay**

Type of delay	Mean	95%CI	Median	min	Max
Centre delay	60.8	42.3-78.8	16	0	358

**6.5.15 Mean Total delay**

The total delay from the onset of symptoms to initiation of treatment in a patient with new sputum positive TB is calculated in the present study. The mean total delay was 104.8 days (95% CI 84.4-125.2) with a range from 5 to 549 days (Table 6.23).

**Table 6.23 Total delay**

<b>Type of delay</b>	<b>Mean</b>	<b>95%CI</b>	<b>Median</b>	<b>min</b>	<b>Max</b>
Total delay	<b>104.8</b>	<b>84.4-125.2</b>	<b>91</b>	<b>5</b>	<b>549</b>

**Summary table of different delay:**

The different levels of delays are listed below in Table 6.24. The maximum delay is after seeking treatment to diagnosis of TB and the next is the patient delay.

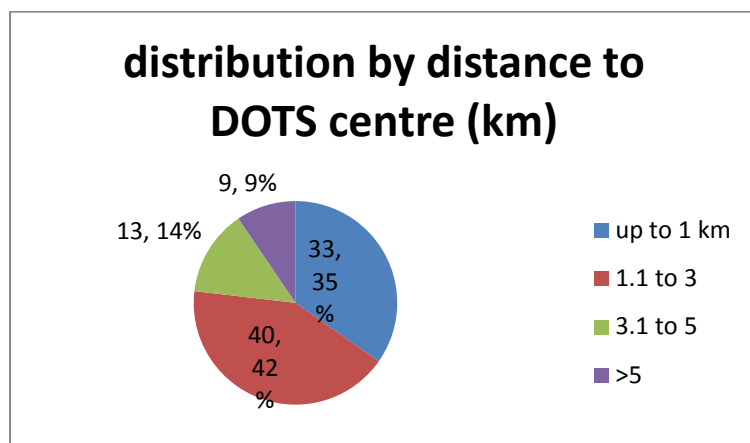
**Table 6.24 Delay**

<b>Type of delay</b>	<b>Mean</b>	<b>95%CI</b>	<b>Median</b>	<b>min</b>	<b>Max</b>
Patient delay in reaching health facility for diagnosis	38.5	25.3-51.6	20	2	540
Centre delay	60.8	42.3-78.8	16	0	358
<b>Health system delay in diagnosing</b>	<b>99.3</b>	<b>79.5-119.1</b>	<b>90</b>	<b>3</b>	<b>547</b>
Treatment delay (after diagnosis to initiating treatment)	2	2.1-3.6	2	0	28
Among the patients who have been referred out, delay in initiating treatment	4.5	1.9-7.1	2	0	60
<b>Total delay</b>	<b>104.8</b>	<b>84.4-125.2</b>	<b>91</b>	<b>5</b>	<b>549</b>

**6.5.15 Distance from home to DOTS**

The proportion of people who said that the distance to DOTS centre 1.1 km to 3 km was 42.1% where as 34.7% patients said the distance to DOTS centre was up to 1 km (Figure 6.8). Mean distance is 2.9 km (95% CI 2.2 to 3.6) and median is 2 km`s.

**Figure 6.8 Distances from Home to DOTS Centre**



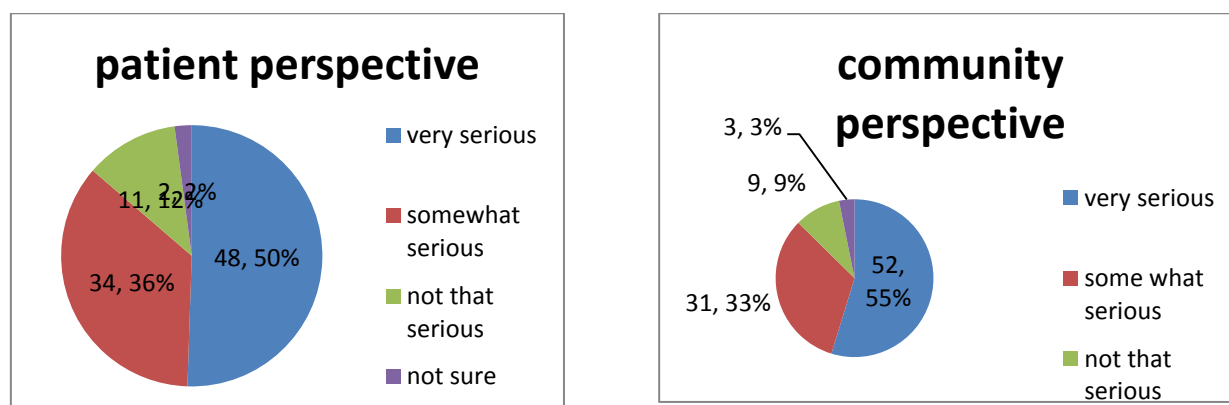
#### 6.5.16 Perception of the patients as they had symptoms of TB

The proportion of the patients who suspected that the symptoms could be because of TB attributes to 22.1% (21). The proportion of patients who heard about TB in their life was 35.8% (34).

#### 6.5.17 Perception of seriousness of the illness by patients:

Among the patients 50.5% of them feel that it is very serious to oneself, 35.8% feels that it is somewhat serious (Figure 6.9). The proportion of who considers TB as very serious in the community is 54.7% and 32.6% considers it as somewhat serious to the community.

**Figure 6.9 Perception of seriousness of TB according to patient and community**



## 6.6 KNOWLEDGE

### 6.6.1 Knowledge of the symptoms of TB among the patients:

Majority of participants with TB know the symptoms. The proportions of the patients who know cough more than 2 weeks and weight loss as symptom of TB is 89.5%. Among the patients 77.9% know loss of appetite as the symptom of TB. 80% of them know evening rise of temperature as symptom of TB. Only 43.2% of them say haemoptysis is a symptom of TB (Table 6.26). Majority of participants without TB knew that cough and loss of weight are symptoms of TB.

### 6.25 Knowledge of the symptoms of TB among the patients:

Symptoms	Participants with TB		Participants without TB
	N	%	No & %
Cough >2 weeks	85	89.5	71
Hemoptysis	41	43.2	62
Weight loss	85	89.5	97
Loss of appetite	74	77.9	66
Fever at evening/night	76	80	46
Chest pain	50	52.6	50

### 6.6.2 Knowledge of transmission of TB:

The proportion of people who said that TB is transmitted by cough and sneeze is 71.6%, 54.7% said that it is transmitted by sharing utensils. Those who said transmission was by touch accounts to 29.5% and 26.3% said it was transmitted by sitting next to someone with TB. Among the general population, knowledge is very high, 98% knew that the transmission is through air (Table 6.26).

**Table 6.26 Knowledge of transmission of TB**

Mode of transmission	Participants with TB		Participants without TB
	N	%	No & %
Cough/sneeze	68	71.6	98
Touch	28	29.5	23
Sitting next to someone with TB	25	26.3	17
Sharing utensils	52	54.7	22
Hereditary	13	13.7	0
Contagious	18	18.9	77

**6.6.3 Knowledge on prevention and cure of TB:**

The proportion of people who said that TB can be prevented by covering while sneezing or coughing was 80%, 74.7% said it could be prevented with good nutrition. Among the general population, 99% knew that covering while coughing/sneezing prevents transmission of TB.

**Table 6.27 Knowledge on prevention and cure of TB**

Mode of Prevention	Participants with TB		Participants without TB
	N	%	No & %
Covering while coughing/sneezing	76	80	99
Avoid sharing meals	61	64.2	56
Good ventilation	57	60	54
Good nutrition	71	74.7	95

96.8% of the participants with TB and 100% of general population m opined that TB can be cured.

#### 6.6.4 Knowledge of treatment and duration of treatment

Among the patients 93.7% said that TB d with regular can be treated with regular medicines, 71.6% said that TB can be cured by proper nutrition (Table 6.28).

The proportion of patients who said duration of the treatment for TB is 6 months was 77.9% and 14.7% of them are not aware of the duration of treatment.

**Table 6.28 Knowledge of treatment and duration of treatment**

Treatment	Variable	N	%
	Regular medicines	86	93.7
	Proper nutrition	68	71.6
Duration of treatment	< 6 months	6	6.4
	6 months	74	77.9
	7 to 9 months	1	1.1
	Not known	14	14.7

#### 6.6.6 Knowledge regarding repeat sputum testing after initiation of sputum

Only 63.2% of the newly sputum positive TB patients were regarding the sputum testing after initiation of treatment, of those who were aware 50% feel that sputum needs to be checked only once (Table 6.29).

**Table 6.29 Knowledge regarding repeat sputum testing after initiation of sputum**

Regarding sputum testing (among patients only)	Variable	N	%
Aware that sputum should be checked	Yes	60	63.2
No of times	Once	30	50
	Twice	19	31.7
	Three times	2	3.3
	Not sure	9	15

#### 6.9.4 Knowledge of timing of repeat sputum sample

Among the 60 patients who were aware of repeat sputum examination 51.7% said that it should be repeated after 2 months and 21.7% of them said that they were not sure.

#### 6.30 Knowledge of timing of repeat sputum testing

Timing of repeat sputum testing	N	%
1 month	9	15
2 months	31	51.7
3 months	5	8.3
6 months	2	3.3
Not sure	13	21.7

Knowledge on timing of testing sputum (follow up) was not much; only 51.7% knew that it should be tested at 2 months. Their knowledge on sputum testing at 6 months is very poor (Table 6.30)

#### 6.7 Knowledge among participants regarding susceptibility to TB

##### 6.7.1 Knowledge among study participants with TB regarding the susceptible individuals for TB

88.4% of the study participants with TB said that anyone can get TB, 30.5 said that people who consume alcohol are highly susceptible to get TB. Among the general population, 95% knew that anyone can get TB.

**Table 6.31 Awareness among participants with TB regarding susceptible individuals for TB**

Who can get tuberculosis	Participants with TB		Participants without TB
	N	%	No & %
Any one	84	88.4	95
People with HIV	10	10.5	2
People with DM	15	15.8	5
People with Alcoholism	29	30.5	10

### 6.7.2 Knowledge scores among participants with TB patients and general community:

Mean knowledge score among people with Tuberculosis was 16.2; SD=3.1 (15.6-16.9). Mean knowledge score among general community was 16.34; SD=2.4 (15.8-16.2).

Poor knowledge was given a score of below 17, average knowledge was given a score of 17-19 and good knowledge was given a score 20 and above.

Among the study participants with TB, 35.8% had poor knowledge and 37.9% had average knowledge. Only 26.3% of them had good knowledge.

Among the study population in the general 44% had average knowledge regarding the disease and only 22% had good knowledge as compared to rest of the population (table 6.32).

**Table 6.32 Knowledge among TB patients and general community**

		<b>TB patients</b>		<b>General community</b>	
		<b>N</b>	<b>%</b>	<b>N</b>	<b>%</b>
<b>Poor</b>	17	34	35.8	34	34
<b>Average</b>	17-19	36	37.9	44	44
<b>Good</b>	>/20	25	26.3	22	22

### 6.8 Perception of Stigma

A validated questionnaire with the 11 items on perception of people living with TB about how community perceive or feel about Tuberculosis (Community Tuberculosis Stigma Perception -11 items) and 12 items on the perception of people living with TB



about how Patients (Person) perceive or feel about TB (Patients' Stigma Perception - 12 items) was administered to the people with TB and people without TB.

After the analysis, the stigma in the community was scored. For the community perception of stigma among the TB patients the mean score was 1.96 with an SD 0.5 and in the general population mean score 1.7 and 0.4 as SD. The percentage mean score was 65.4 with 16.7 among TB patients; in the general population it was 59.9 and the standard deviation was 12.8 (Table 6.33). For the patient perception of stigma among the TB patients the mean score was 1.8 with an SD 0.4 and in the general population mean score 1.8 and 0.3 as SD. The percentage mean score was 59.24 with 14.5 among TB patients; in the general population it was 59.8 and the standard deviation was 9.7.

**Table6.33 Stigma in the study population**

	<b>TB patients</b>		<b>General community</b>	
	<b>MEAN</b>	<b>SD</b>	<b>MEAN</b>	<b>SD</b>
Community perspectives toward tuberculosis - Mean score	1.96	0.5	1.7	0.4
Community perspective towards tuberculosis-% mean score	65.4	16.7	59.9	12.8
Patient perspectives toward tuberculosis – Mean score	1.8	0.4	1.8	0.3
Patient perspective toward tuberculosis - % mean score	59.24	14.5	59.8	9.7

Stigma was further classified as mild, moderate and severe. A score of less than 1.75 was considered as mild stigma, 1.75-1.99 was considered as moderate stigma and a score of more than or equal to 2 was classified into severe stigma.

Among participants with TB, nearly 50% had severe level of stigma (patient perspective) and 35.8% had moderate level. In the general community, 57% had moderate and 12% had severe level of perceived stigma (patient perspective).

**Table: 6.34 Stigma in patient perspective categorized**

Level of stigma	Score	TB patients		General community	
		N	%	N	%
Mild	<1.75	14	14.7	31	31
Moderate	1.75-1.99	34	35.8	57	57
Severe	>/2	47	49.5	12	12

The level of stigma (community perspective) according to patient was severe in 33.7% and moderate in 30.5% where as in the general community, 45% severe and 33% moderate (Table 6.35).

**Table: 6.35 stigma in community perspective categorized**

Level of stigma	score	TB patients		General community	
		N	%	N	%
Mild	<1.75	34	35	22	22
Moderate	1.75-1.99	29	30.5	33	33
Severe	>/2	32	33.7	45	45

## 6.9 Measurement of associations:

In the present study, the association between knowledge and various factors was carried out on all the 195 participants (patients + general community) who were interviewed. Odds of exposure to various factors such as age, gender, education, occupation, socio economic status (SES), residential status, h/o TB (past and family), drinking and smoking; for knowledge were calculated by univariate analysis and 95% confidence interval was estimated. Age, gender did not show any significant

association with knowledge (Table 6.36). Those with lower education chose to do unskilled jobs or stay unemployed and eventually reflect in lower socioeconomic strata; and show chance of low knowledge which was not statistically significant.

### 6.9.1 Knowledge in study population

**Table 6.36 Knowledge (n=195) in study population**

Variable	Categories	Knowledge		p-value	Unadjusted OR & 95%CI	Adjusted OR & 95%CI
		Low (%)	High (%)			
Age	Upto 35	21(43.8)	27(56.2)	0.137	0.6 (0.31-1.15)	0.698 (0.32-1.52)
	> 35 years	83(56.5)	64(43.5)			
Sex	Female	40(51.3)	38(48.7)	0.663	0.87 (0.491-1.54)	0.711 (0.32-1.58)
	Male	64(54.7)	53(45.3)			
Education	Upto 5	50(60.2)	33(39.8)	0.111	1.627 (0.916-2.89)	1.655 (0.79-3.46)
	>5 <sup>th</sup> class	54(48.2)	58(51.8)			
Occupation	Nil/Unskilled	43(58.9)	30(41.1)	0.239	1.433 (0.798-2.576)	1.219 (0.61-2.43)
	Others	61(50.0)	61(50.0)			
SES	Low	66(53.2)	58(46.8)	1.000	1.012 (0.564-1.816)	1.370 (0.69-2.72)
	Middle	38(53.5)	33(46.5)			
Residence	Urban	2(40.0)	3(30.0)	0.666	0.575 (0.094-3.52)	0.49 (0.07-3.33)
	Rural	102(53.7)	88(46.3)			
Smoking	Ever	35(51.5)	33(48.5)	0.764	0.89 (0.494-1.60)	0.564 (0.22-1.47)
	Never	69(54.3)	58(45.7)			
Alcohol	Ever	29(52.7)	26(47.3)	0.967	1.000 (0.517-1.80)	1.07 (0.43-2.69)
	Never	75(53.6)	65(46.4)			
TB	Present	5(71.4)	2(28.6)	0.452	2.247 (0.425-11.8)	0.741 (0.43-2.72)
	Absent	99(52.7)	89(47.3)			
Family history of TB	Present	10(52.6)	9(47.4)	0.949	0.969 (0.376-2.501)	0.74 (0.25-2.20)
	Absent	94(53.4)	82(46.6)			

### 6.9.2 Perception of stigma:

Stigma is one of the hindrances for the control of tuberculosis. On univariate analysis of community perception of stigma among 195 study participants (patients + general) with various factors such as age, sex, marital status, education and other factors as shown in the table 6.37. It was found that perception of stigma was more among men.

In the same way ever smokers and people with TB perceive more stigma as compared to others.

**Table 6.37 Community perception of stigma related to TB (N=195)**

Variable	Categories	Stigma		p-value	Unadjusted OR & 95%CI
		High	Low		
Age	Upto 35	12(25.0)	36(75.0)	0.469	1.410 (0.673-2.954)
	> 35 years	47(32.0)	100(68.0)		
Sex	Female	15(19.2)	63(80.8)	0.007*	2.532 (1.29-4.98)
	Male	44(37.6)	73(62.4)		
Education	Upto 5	29(34.9)	54(65.1)	0.270	0.681 (0.37-1.26)
	>5 <sup>th</sup> class	30(26.8)	82(73.2)		
Occupation	Nil/Unskilled	22(30.1)	51(69.9)	1.000	1.009 (0.537-1.898)
	Others	37(30.3)	85(69.7)		
SES	Low	45(36.3)	79(63.7)	0.016*	2.319 (1.164-4.623)
	Middle	14(19.7)	57(80.3)		
Residence	Urban	1(20.0)	4(80.0)	1.000	1.758 (0.192-16.06)
	Rural	58(30.5)	132(69.5)		
Smoking	Ever	32(47.1)	36(36)	<0.001*	0.304 (0.160-0.575)
	Never	27(21.3)	100(78.7)		
Alcohol	Ever	24(43.6)	31(56.4)	0.015	0.431 (0.223-0.830)
	Never	35(25.0)	105(75.0)		
Marital status	Unmarried	11(52.4)	10(47.6)	0.025	2.88 (1.152-7.236)
	Ever married	48(27.6)	126(72.4)		
Family history of TB	Present	5(26.3)	14(73.7)	0.798	1.239 (0.425-3.614)
	Absent	54(30.7)	122(69.3)		
Knowledge	Low/Average	25(24)	79(76.0)	0.060	1.885 (1.015-3.499)
	High	34(37.4)	57(62.6)		
Presence of TB	Present	12(12.0)	88(88.0)	<0.001 *	0.139 (0.067-0.288)
	Absent	47(49.5)	48(50.0)		

\* Statistically significant

### 6.9.3 Multivariate analysis for perception of stigma:

A multivariate analysis is performed on the variables which showed statistically significant in univariate analysis. The variable includes sex (p value 0.007, OR=2.532

& 95% CI 1.29-4.98); SES (p value 0.016, OR=2.319 & 95% CI 1.164-4.623); smoking (p value <0.001, OR=0.304 & 95% CI 0.160-0.575); alcohol (p value 0.015, OR=.431 & 95% CI 0.223-0.830); marital status (p value 0.025, OR 2.88 & 95% CI 1.152-7.236); presence of TB (p value <0.001, OR 0.139 95% CI 0.067-0.288). On adjusting for the above mentioned variables as shown in the table 6.38, only people with TB were found to have more perception of stigma, which was statistically significant.

**Table:6.38 Logistic regression model for factors associated with community perception**

Variables	Categories	Perception of stigma		P value	OR 95% CI	AOR 95% CI
		High	Low			
Sex	Female	15(19.2)	63(80.8)	0.406	2.532 (1.29-4.98)	0.663 (0.252-1.745)
	Male	44(37.6)	73(62.4)			
SES	Low	45(36.3)	79(63.7)	0.104	2.319 (1.164-4.623)	0.531 (0.247-1.140)
	Middle	14(19.7)	57(80.3)			
Smoking	Ever	32(47.1)	36(36)	0.152	0.304 (0.160-0.575)	2.293 (0.738-7.125)
	Never	27(21.3)	100(78.7)			
Alcohol	Ever	24(43.6)	31(56.4)	0.348	0.431 (0.223-0.830)	0.590 (0.196-1.777)
	Never	35(25.0)	105(75.0)			
Marital status	Unmarried	11(52.4)	10(47.6)	0.150	2.88 (1.152-7.236)	2.201 (0.75-6.45)
	Ever married	48(27.6)	126(72.4)			
Patients with TB/ general community	Patient with TB	12(12.0)	88(88.0)	<0.001*	0.139 (0.067-0.288)	0.199 (0.088-0.451)
	General community	47(49.5)	48(50.0)			

\* Statistically significant

#### 6.9.4 Perception of stigma in study participants with TB:

The perception of stigma among 195 participants is studied with the help of 12 point stigma scale – a validated tool from van Rie et al study. In the univariate analysis as well as after adjusting for odds with various factors as shown in the table people with

good knowledge has more perception of stigma which is statistically significant (Table 6.39). It could probably be explained as they know the symptoms of TB they have many associated fears with it.

**Table:6.39 Perception of stigma in study participants with TB**

Variable	Categories	Stigma		p-value	Unadjusted OR & 95%CI
		High	Low		
Age	Upto 35	14(29.2)	34(70.8)	0.125	1.821 (0.902-3.67)
	> 35 years	63(42.9)	84(57.1)		
Sex	Female	29(37.2)	49(62.8)	0.655	1.715 (0.652-2.118)
	Male	48(41.0)	69(59.0)		
Education	Upto 5	38(45.8)	45(54.2)	0.139	0.633 (0.354-1.31)
	>5 <sup>th</sup> class	39(34.8)	73(65.2)		
Occupation	Nil/Unskilled	31(42.5)	42(57.5)	0.547	0.820 (0.454-1.48)
	Others	46(37.7)	76(62.3)		
SES	Low	54(43.5)	70(56.5)	0.132	1.610 (0.874-2.965)
	Middle	23(32.4)	48(67.6)		
Residence	Urban	1(20.0)	4(80.0)	0.650	2.667 (0.292-24.3)
	Rural	76(40.0)	114(60.0)		
Smoking	Ever	28(41.2)	40(38.8)	0.760	0.897 (0.492-1.636)
	Never	49(38.6)	78(61.4)		
Alcohol	Ever	23(41.8)	32(58.2)	0.745	0.874 (0.463-1.64)
	Never	54(38.6)	86(61.4)		
Marital status	Unmarried	9(42.9)	12(57.1)	0.815	1.169 (0.468-2.923)
	Married	68(39.1)	106(60.9)		
Family history of TB	Present	6(31.6)	13(68.4)	0.622	1.465 (0.532-4.035)
	Absent	71(40.3)	105(59.7)		
Knowledge	Low/Average	31(29.8)	73(70.2)	0.003*	2.40 (1.33-4.33)
	High	46(50.5)	45(49.5)		
TB	Present	3(42.9)	4(57.1)	1.000	0.865 (0.19-3.78)
	Absent	74(39.4)	114(60.6)		

\* Statistically significant

### 6.9.5 Factors affecting delay in study participants with TB

Delay with a cut off taken as 30 days is categorised to delay of < 30 days and delay of > 30 days. To measure the association with various factors as shown in the table both univariate and multivariate analysis was performed. The determinants of delay include

socio-demographic variables like age, gender, education, occupation, type of house, type of family and economic status of the family.

**Table: 6.40 Factors affecting delay in diagnosis and initiation of treatment in TB patients**

Variable	Categories	Delay		p-value	Unadjusted OR & 95% CI
		> 30 days(%)	<30 days(%)		
Age	Upto 35	14(56)	11(44)	0.257	1.714 (0.672-4.376)
	> 35 years	48(68.6)	22(31.4)		
Sex	Female	14(58.3)	10(41.7)	0.410	1.49 (0.576-3.86)
	Male	48(57.6)	23(32.4)		
Education	Upto 5	31(66.0)	16(34.0)	1.000	0.941 (0.404-2.19)
	>5 <sup>th</sup> class	31(64.6)	17(35.4)		
Occupation	Nil/Unskilled	32(74.4)	11(25.6)	0.088	0.469 (1.104-6.987)
	Others	30(57.7)	22(42.3)		
SES	Low	49(72.1)	19(27.9)	0.034*	2.77 (1.922-42.56)
	Middle	13(48.1)	14(51.9)		
Residence	Urban	3(60.0)	2(40.0)	0.800	1.269 (0.201-7.99)
	Rural	59(65.6)	31(34.4)		
Smoking	Ever	36(69.2)	16(30.8)	0.372	0.680 (0.291-1.59)
	Never	26(60.5)	17(39.5)		
Alcohol	Ever	31(70.5)	13(29.5)	0.324	0.650 (0.276-1.532)
	Never	31(60.8)	20(39.2)		
Family history of TB	Present	9(56.2)	7(43.8)	0.409	1.585 (0.531-4.732)
	Absent	53(67.1)	26(32.9)		
Knowledge	Low/Average	38(71.7)	15(28.3)	0.193	0.526 (0.224-1.237)
	High	24(57.1)	18(42.9)		
Stigma- community	Low/Average	28(58.3)	20(41.7)	0.197	1.868 (0.791-4.410)
	High	34(72.3)	13(27.7)		
Stigma – patient	Low/Average	39(61.9)	24(38.1)	0.371	1.573 0.625-3.959
	High	23(71.9)	9(28.1)		
Distance to health centre	Upto 1 Km	22(66.7)	11(33.3)	1.000	0.909 (0.373-2.217)
	>1 Km	40(64.5)	22(35.5)		
Debt due to medical expenses	Present	32(82.1)	7(17.9)	0.005*	0.252 (0.095-0.667)
	Absent	30(53.6)	26(43.4)		
No. health facilities visited	>2 centres	40(83.3)	8(16.7)	<0.001*	5.682 (2.195-14.7)
	Upto 2 centres	22(46.8)	25(53.2)		
Health seeking behavior	Self/chemist	21(58.3)	15(41.7)	0.278	0.615 (0.259-1.458)
	Health centre	41(69.5)	18(30.5)		
Health facility	Private	43(70.5)	18(29.5)	0.181	0.530 (0.222-1.269)
	TB centre	19(55.9)	15(44.1)		

\* Statistically significant

From the above table, patients from lower socio economic status had experienced more delay as compared to middle socio economic status. It was statistically significant with a p-value of 0.034 and odds ratio of 1.5 which shows those of low S.E.S had 2.77 times higher chance of delay more than 30days for treatment of TB.

Patients who had taken more debts due medical expenses had also experienced more delay with a p-value of 0.005 and odds ratio of 1.5. This was statistically significant and shows that those who had debts due to medical expenses tend to have 2.77 times higher chance of being delayed in acquiring treatment with in adequate time.

#### 6.9.6 Multivariate analysis for delay

**Table:6.41 Multivariate regression model for delay**

Variable		Delay		P value	OR 95% CI	AOR 95% CI
		>30 days	<30 days			
Debt due to medical expenses	Present	32(82.1)	7(17.9)	0.433	0.252 (0.095-0.667)	0.628 (0.196-2.010)
	Absent	30(53.6)	26(43.4)			
No. health facilities visited	>2 centres	40(83.3)	8(16.7)	0.004*	5.682 (2.195-14.7)	5.342 (1.699-16.802)
	Upto 2 centres	22(46.8)	25(53.2)			
Socio economic status	Low	49(72.1)	19(27.9)	0.278	2.77 (1.922-42.56)	3.370 (1.162-9.778)
	Middle	13(48.1)	14(51.9)			

\* Statistically significant

Among the 95 patients in the study those who had to visit more than 2 health centres found to have 5.77 times more chances of delay to the treatment as compared to other who contacted at least 2 health centres for the treatment, which was statistically significant.



On adjusting for various other factors as shown in the table, people with low S.E.S, who had debts due to medical expenses and those who had to visit more than 2 health centres were found to statistically significant.

This could be explained as patients from lower economic status due to poverty had often visited local doctors, waited with the anticipation that symptoms would get better with the available treatment. But this eventually prolonged the duration and severity of symptoms and led to more debts as they lost their daily wages due to sickness. The present study gives a significant result that poverty is still the main reason for this vicious circle of the disease

## **7. Discussion**

Tuberculosis is a preventable as well as curable disease. Since the disease is contagious; it stands as a global health problem. The disease is highly wide spread(45).Under W.H.O initiative with DOTS, to increase success of TB treatment it emphasizes on passive case finding. Since the passive case finding depends on their willful appearance before the health facility which indirectly reflects on their health seeking behaviour. In a scenario like this there are high chances of delay in seeking health care with onset of symptoms(14).

The delay in approaching a health care provider with initiation of symptoms will increase the bacillary load and pose a threat to increased transmission of the disease. Each of the infected patients with smear positivity are highly infective and has the potential to infect 10 other people in their life time(8).Prolonged delay can lead to increased infectivity in the community and severe morbidity(46).

Hence the present study aimed at identifying the causes of delay. This is important in case detection and further elimination of the disease. If case finding is improved, it may save lives 10 times as DOTS alone(16).

The present study is a cross sectional study done to analyze the factors affecting the delay in diagnosis and initiation of treatment in newly diagnosed sputum positive pulmonary tuberculosis who registered under CHAD-TU during the period of November 2014 to May 2015. One of the major risk factor for delay, as perceived from various studies is stigma(35).The level stigma in the community as well as in the patient group is analyzed.

In the present study among the 95 patients those who had to visit more than 2 health centers were found to have 5.77 times more chances of delay to the treatment as compared to other who contacted at least 2 health centers for the treatment, which was statistically significant. Low SES and debts due to medical expenses were found to have significant association with delay in diagnosis of treatment (univariate analysis).

Several studies show that repeated visits to health centers or same health centre at the same level is the main problem for delay in diagnosis or initiation of treatment(9). This is a vicious circle that causing delay, in Burkina Faso since specialized services were poor many of the patients had repeated consultations at the same level of health care(47). In Ghana the health personnel were under trained; hence proved to be reason for delay and was correlated with failure to do sputum microscopy ( $r=0.99$ ) (48). In a study done in Malaysia only 11% of the patients were diagnosed in the initial and 45% of them in the third consultation(49). In another study done in Malaysia sputum microscopy, chest X-ray were underutilized and indicating low awareness of private practitioners(50). A similar report was found in New Zealand study thought the patient had classical symptoms at least no sputum microscopy was not performed(51).

The mean delay in the present study in reaching the health facility is 38.5 days and median is 20 days which is similar as compared to studies done in similar settings in Pakistan and United States. The total delay till diagnosis (median 90 days) is also similar as compared to studies in Malaysia, Pakistan and the US.

TABLE:6.42 MEDIAN DIAGNOSTIC DELAY IN COMPARISION WITH OTHER STUDIES

Country	Year	First author	DDPAT	DDHC	Tot DD	Reference
<b>PRESENT STUDY</b>			20	16	90	
Tanzania	2000	Wandwalo	15	120	136	(36)
United kingdom	2003	Lewis	63	36	126	(52)
Burkina Faso	2006	Ouedraogo	*	*	120	(51)
Ghana	1998	Lawn	28	56	120	(53)
Pakistan	2006	WHO	9	87	91	(54)
Malaysia	1994	Hooi	15	35	90	(49)
United States	2005	Golub	32	26	89	(55)

DDPAT-Patient delay (time from first onset of symptoms to first visit to health centre/provider

DD HCP-health care provider delay (Diagnostic Delay by the Health Care Providers): Time taken from first visit to a HC till the making of a proper diagnosis

DD Total (Total Diagnostic Delay): Time from onset of symptoms till proper diagnosis

\*unavailable

### **7.1 Socio demographic profile characteristics:**

Majority of the patients interviewed were men, predominantly (90%) from rural area. Inclusion criteria being those of more than 18 years of age, 25.3% of them belong to age group of 18 to 35 years 48.4% of them falls to 35 to 60 years age group with rest of them belonging to above 60 years of age.

Higher proportion of the subjects have nil or education up to primary school only. Of the study population majority were unemployed; of which 29.5% are unskilled daily wage labourers; 94.7% hail from rural background.

In the general population 44% of them were above 60 years; 54% female and entire study population was from rural background.

### **7.2 Personal characteristics:**

Smoking is predominantly abused by 54.9% of them (current and past smokers); most of them are current smokers. They were smokers for more than 30 years and been smoking at least 11 to 10 cigarettes/beedis per day. Most of them smoked beedis as they were of low price.

A proportion of 46.3% of them were alcohol abusers, among those who abused alcohol 20.5% of them consumed more than 2000ml of alcohol per day. Due to heavy consumption of alcohol, there were patients who found to have defaulted in the later months. There were 2 deaths which later came to notice with a similar issue.

Patients had multiple symptoms as they showed up in the health facilities. Cough (93.7%), fever (85.3%), loss of weight (84.2%) and loss of appetite (83.2%),

haemoptysis (22.1) and chest pain (18.9%) were the symptoms as mentioned by them. But only 40% of them sought treatment as they had cough and 28.4% for fever. In a study done in central India 94% of the patients complained of cough more than 2 weeks(56).

A large proportion of them sought health centers with the onset of symptoms of which 43.2% approached private hospitals and rest to various government health facilities such as PHC (12.6%) with the onset of symptoms. The similar finding was found in a study done in central India where private providers were visited more often than government health centers (63.5% vs. 31.2%;  $P < 0.001$ ) (17). In a study done in ten districts of Tigray region, Ethiopia; showed that 54% of the patients received help from formal health providers(57).

The time taken for the patient to approach health facility with the onset of symptoms is taken as patient delay. The mean patient delay was 38.5 days. Most of them thought it was not necessary (50%) to approach health centre early and tried self-medication (29.4%). Even in a study done in Bahir Dar city, Ethiopia they found multiple reasons attributing to delay (mean delay 21 days) such as (90%) thought that symptoms would disappear and in others it was due to financial problem (28.4%)(58).

Among the patients group one person (1.1%) tried and waited using `Sidda` medicine as he himself was Sidda provider. In a study done in Ethiopia 1.2% approached traditional healers(59). This shows there is a group which still waits on traditional medicine for the cure of TB. Association between patients delay and non-formal health providers was statistically significant and it increased health system delay in an

Ethiopian study (25) One of the patient in the study group delayed as he was misdiagnosed with typhoid in the initial centre, later was told to have dengue/chickungunya for his consistent symptom of fever and only was diagnosed when he finally reached a higher centre (GVMCH). In this patient the delay was almost 3 years duration. In a study done in Gambia TB is often misdiagnosed as malaria or viral infection(60).

Health care facility where patient first sought treatment for TB was private hospital (64.2%).The initial diagnosis of TB was made by GVMC (Government Medical College-Vellore) for a proportion of 35.8% and 32.6% of the patients were diagnosed in CHAD.

Out of the interviewed 58.9% of them did not have any debts due to medical expenses, but 21.1% of them had debts in the range of Rs.10001 to 50000. Money spent on approaching health providers for treatment with both direct and indirect costs was counted. Total cost before diagnosis spent by 38.9% of them was up to Rs.500; only 2 of them spent money of more than Rs.50, 000 before diagnosis. In the present study patients who had taken more debts due medical expenses had also experienced more delay with a p-value of 0.005 and odds ratio of 1.5. This was statistically significant and shows that those who had debts due to medical expenses tend to have 2.77 times higher chance of being delayed in acquiring treatment with in adequate time.

Accessibility was the reason in 62.1% of them; while 31% of them chose as they had more confidence in that particular provider.

Sputum examination was done in 98.9%, blood tests were done in 96.8% of them where as 88.4% of them also had chest x-rays taken. This shows that almost all facilities they approached had the required laboratory tests available to diagnose the disease adequately. But the only gap was that there was delay in approaching the right facility. In the present study the mean diagnostic delay or treatment delay was 2 days.

The proportion of 47.4% patient`s thought it was not necessary to go to these centers where as 27.4% of them couldn't go as they have no money. But 9 of them have immediately approached their regular health provider and waited to be cured of the sickness until they were diagnosed of TB. The proportion of patients who experienced a delay of 91-180 days was 26.3%.

A delay of 31-90 days in diagnosis of the disease was experienced by 24.2% of them. Among those who had delayed; a proportion of 67.4% responded that they consider it as delay. The proportion of people who were 1.1 km to 3 km away from DOTS centre (facility) were 42.1% ; where as those that were 1 km away were 34.7%.Mean distance from home to DOTS center is 2.9 km (95% CI 2.2 to 3.6) and median is 2 km.

The time taken from the first onset of symptoms to till it was diagnosed is health system delay, and the mean health system delay was 99.3 days.

In the present study, age, gender did not show any significant association with knowledge. Those with lower education chose to do unskilled jobs or stay unemployed and eventually reflect in lower socioeconomic strata; and show chance of low knowledge which was not statistically significant.



Stigma is one of the hindrances for the control of tuberculosis. On univariate analysis of community perception of stigma among 195 study participants (patients + general) with various factors such as age, sex, marital status, education and other factors as shown in the table below. It was found that perception of stigma was more among men. In the same way ever smokers and people with TB perceive more stigma as compared to others. But after adjusting for various factors as shown in the table only people with TB were found to have more perception of stigma, which was statistically significant. It could probably be explained as they know the symptoms of TB they have many associated fears with it.

Patients from lower economic status due to poverty had often visited local doctors, waited with the anticipation that symptoms would get better with the available treatment. But this eventually prolonged the duration and severity of symptoms and led to more debts as they lost their daily wages due to sickness. The present study gives a significant result that poverty is still the main reason for this vicious circle of the disease.

## **7. Limitations**

1. Recall bias could be a possibility; though care was taken to visit patients within 2 weeks of recruitment.
2. Most of the patients were very sick and tired of the illness, in few of them their responses were influenced by the care giver as they couldn't recollect.
3. In the general population people in few villages were completely unaware of the disease and not seen any patient in their village, they all answered as no stigma. Hence perception of stigma and knowledge of the disease are directly related.
4. Due to the nature of the cross sectional study design underreporting or over reporting of patient delay is unavoidable.
5. This hospital-based study cannot provide information on individuals who were never treated in hospital and who may die untreated in the community.

## 9. Conclusions

The present study aimed at identifying the factors affecting delay in diagnosis and delay in initiation of treatment in a newly diagnosed sputum positive patient.

We included 95 patients with TB and 100 from general population to know stigma in community. The mean total delay, patient delay, health system delay, centre delay and treatment delay were 104.8, 38.5, 99.3, 60.8 and 2 days respectively. The median total delay, patient delay, health system delay, centre delay and treatment delay were 91, 20, 90, 16, 2 days respectively.

This study shows that health care providers do not suspect TB in first contact, and investigate for TB and miss on the symptoms. Poor knowledge on TB and stigma related to TB also contribute to the delay, awareness creation to the general population regarding the treatability and complete cure if diagnosed and treated early is important to prevent delay in diagnosis.

People with TB were found to have more perception of stigma. People with good knowledge had more perception of stigma in the community. Other factors that independently associated with delay were low SES and number of health centers visited.

## **10. Recommendations**

The main reason for delay in diagnosis which is identified through the present study is number of health facilities consulted before the diagnosis. This shows that the health care providers do not suspect TB at the first visit and treat them without investigating for TB. Hence, patients visit multiple providers and loose time before diagnosis. As per RNTCP, sputum testing is the main strategy for diagnosis. However, this study showed that most people had X-ray before diagnosis. Due to inappropriate treatment either due to lack of facilities or expertise causes doctor shopping. Hence, regular Continued Medical Education programs may improve health personnel's' ability to diagnose TB earlier.

Poor knowledge on TB and stigma related to TB also contribute to the delay. Hence, awareness creation to the general population regarding the treatability and complete cure if diagnosed and treated early is important to prevent delay in diagnosis.

People from low socio economic strata are at risk of developing TB and this study reveals that SES is a significant factor for delay in diagnosis. People from low socio economic status are forced to attend local health providers for treatment due to financial problems and would eventually delay diagnosis. Hence, along with creating awareness, screening programs for active case finding may be arranged at the community level.

Finally, health workers should be made aware of the symptoms and also the adverse effects if left untreated, so that they will be able to encourage the patients to choose right health facility.

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## 12. Annexures

### Annexure 1

#### Patient information sheet

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(Applicable for the participants  $\geq 18$  years of age)

The following information is provided to inform you about this research project and your participation in it. Please read this form carefully and please feel free to ask any questions you may have about the study or the information given below. You will be given an opportunity to ask questions, and your questions will be answered. Also, you will be given a copy of this information sheet.

Your participation in this research study is voluntary. You are also free to withdraw from this study at any time after it starts.

Purpose of the study:

Tuberculosis is a curable disease but it spreads rapidly. If diagnosed and treated on time the chain of transmission can be stopped. This study is to find out the various difficulties involved in seeking medical help in time and receiving treatment on time.

Methods to be followed

We will ask you questions to know when the actual disease process started in you and when you first sought medical help. These questions help to identify various issues involved in delay in seeking medical help.

Approximate duration of study

Five months (December 2014 to April 2015)

Expected cost

We will not incur any cost due to your participation in the study

Descriptions of the discomforts, inconveniences, and/or risk factors that can be reasonably expected as a result of participation in the study:

The questions that we ask you may not cause any discomfort to you as these are focussed only to understand the issues involved in delay in finding out the problem and getting treated for it. To avoid any inconvenience, I will meet in the place of your convenience either at DOTS clinic or your home.

#### Unforeseeable risks

There are no such risks involved as adequate measures are taken to meet you on your convenient time and convenient place.

#### Compensation in view of study related injury

We do not expect any injury related to this and hence will not be compensating you monetarily

#### Anticipated benefits from this study:

The main purpose of the study is to find various issues involved in delay in the diagnosis of TB, in spite of government's active interventions in reaching out to help. As we interview you we will be able to identify required information. This study and the interview we conduct is as much as a mutual exchange of knowledge where your awareness about TB will increase. By participation in the study, participants' awareness and knowledge about disease transmission and treatment will improve. Compliance to treatment will also improve and efforts to reduce their perception on stigma can be done. Any associated illness or noncompliance of the participant can be taken care of by the team at base hospital with the consent of the participant where free treatment can be given.

After the focus group discussions, the community's awareness can be identified and knowledge can be imparted

#### Compensation for participation:

We will not give money to answer questions or be a part of this study.

#### Circumstances under which the principal investigator may withdraw you from the study participation:

If you wish not to answer questions or do not want us to contact or meet regarding this particular study we can withdraw you from this study. If you withdraw, this will not stop us from providing medical care for you or your family.

#### What happens if you choose to withdraw from the study participation?

The information you give us will not be used by us. All collected information will be destroyed.

**Confidentiality:**

All efforts, within reason, will be made to keep your personal information in the research record confidential. It will not be shared with anyone else.

**Privacy**

Your identity will not be revealed to anyone else; however summary data of the study may be shared with Institutional Review Board of Christian medical college and used for publication for scientific purpose.

**Contact information:**

If you have any questions about this research study or possibly, please feel free to contact:

Dr.Harika 09159152270    or    Dr.Manjunath 09894262107    or Dr.Jasmine  
9442382466

## Annexure 2

### Consent form

---

Study title: To study barriers in early diagnosis and initiation of treatment in people with tuberculosis in Southern India.

Date:

Study number:

Name of the study participant:

Father/mother/husband/partner`s name:

Age:

Village:

- I have read information sheet / i have been informed by the investigator that this study is carried out to find out the barriers in delay of early diagnosis and thereafter initiation of treatment in people affected with the rural tuberculosis. I have understood that the result of the study is to increase the awareness among the community. Also to identify the reasons in delay of treatment, this is very essential to reduce the transmission of disease to achieve a healthy community.
- I understand that my participation in this study is purely voluntary. My unwillingness to participate or decision to withdraw will not affect my (family) current or future care with any of the programme the investigators institution.
- I understand that my privacy will be maintained and all information given by me will be kept confidential and be used for the purpose of the study only. However summary results for this study may be shared with for publication purposes.

- I understand that the investigator and the other researchers will not need my permission to look at my study information both in the current study and any further research that may be conducted in relation to it. I agree to this access. However, i understand that my identity will not be revealed in any investigation released to third party investigator or if this study is published.
- I confirm that i have read (or have read to me in my own language )and understood the information sheet for the above study and have had the opportunity to ask questions.
- I agree the investigators contacting me over the phone and meeting me personally to know the details related to my illness

Signature / thumb impression of the participant: -----

Signature of the witnesses:-1. -----2. -----

Signature of the investigator: -----

If you have any questions about this research study, please contact

Dr.Harika: o9159152270

My advisors:

Dr.Manjunath:09894262107

Dr.Jasmine:09442382466



## Annexure 3

டி பி நோய் குறித்து கருத்தெடுக்கும் படிவம்

ஆ. பொதுவான கேள்விகள்

1. நேரில் சந்தித்து பேசும் நாள்
2. வரிசை எண்
3. ஊர் பெயர்
4. டிபி பதிவேடு எண்
5. பெயர்
6. வயது
7. இனம் 1)ஆண் 2)பெண்
8. குடும்பத்தில் எத்தனை நபர்
9. குடும்பத்தில் எத்தனை அறை
10. ஆய்வில் பங்கெடுப்பவரின் கல்வி
11. துணைவர்/துணைவி கல்வி
12. நோய் அறிகுறிக்கு முன் ஆய்வில் பங்கெடுப்பவரின் தொழில்
13. நோய் அறிகுறிக்கு முன், ஆய்வில் பங்கெடுப்பவரின் வருமானம்
14. ஆய்வில் பங்கெடுப்பவரின் தற்போதைய தொழில்
15. ஆய்வில் பங்கெடுப்பவரின் தற்போதைய வருமானம்
16. துணைவர்/துணைவி தொழில்
17. குடும்ப வருமானம் (நோய் அறிகுறிக்கு முன்பு)
18. குடும்ப வருமானம் (தற்போது)
19. வீடு 1) குடிசை 2. ஓலை வீடு 3. ஓட்டு வீடு 4. மெத்தை வீடு
20. மருத்துவ செலவினால் எவ்வளவு கடன் மொத்தமாக உள்ளது
21. உறைவிடம் 1)கிராமம் 2) பட்டினம் 3) சேரி 4) வீடில்லாதவர்
22. திருமணம் 1) ஆகாதவர் 2) ஆனவர் 3) விவாகரத்து/தனிமை 4)விதவை
23. புகை பழக்கம் 1) ஒருபோதும் இல்லை 2) முன்பு 3) தற்போது
24. கேள்வி 20க்கு, 2 அல்லது 3 என்றால், தினம் எத்தனை
25. கேள்வி 20க்கு, 2 அல்லது 3 என்றால், எத்தனை காலமாக
26. குடி பழக்கம் 1) ஒருபோதும் இல்லை 2) முன்பு 3) தற்போது
27. கேள்வி 23க்கு, 2 அல்லது 3 என்றால், எத்தனை காலமாக
28. கேள்வி 23க்கு, 2 அல்லது 3 என்றால், தினம் எவ்வளவு
29. இதற்கு முன் டிபி பாதிப்பு ஏற்பட்டுள்ளதா 1) இல்லை 2) ஆம்  
(விவரக்கவும்)
30. குடும்பத்தில் யாருக்காயினும் டிபி பாதிப்பு ஏற்பட்டுள்ளதா 1) இல்லை 2) ஆம்
31. வேறு ஏதேனும் நோய் உள்ளதா 1)இல்லை 2)ஹெச்ஐவி 3)சர்க்கரை  
4) நாளப்பட்ட நுரையீரல் அடைப்பு 5) மற்றவை

சிகிழ்சை குறித்தான விவரங்கள்

3.2. கீழ்க்கண்ட அறிகுறி ஏதேனும் உங்களுக்கு உள்ளதா.

குறி எண்	அறிகுறி	ஆரம்பித்த தினம்	எத்தனை நாட்கள்
1	இருமல்		
2	ஜீரம்		
3	எடை குறைவு		
4	பசியின்மை		
5	இருமலில் இரத்தம்		
6	மார்பு வலி		
7	பிற		

3.3. மேற்குறிப்பட்ட அறிகுறியில் எது உங்களை மருத்துவ சிகிழ்சைக்கு போக வைத்தது

3.4. நோய் அறிகுறி ஆரம்பித்த பின்னர், நோய் கண்டறியப் படுமுன் நீங்கள் எங்கு சிகிழ்சைக்காக சென்றீர்கள். எவ்வளவு செலவு செய்தீர்கள்

சிகிழ்சை பார்த்த இடம்	சென்ற தேதி	சிகிழ்சையின் முடிவு	சிகிழ்சையின் முடிவு அங்கு செல்ல காரணம்	மொத்த செலவு

குறி எண்

குறி எண்	சிகிழ்சை பார்த்த இடம்	குறி எண்	சிகிழ்சையின் முடிவு	குறி எண்	அங்கு செல்ல காரணம்
0	செல்லவில்லை	0	பொருந்தாது	0	பொருந்தாது
1	தானாகவே வைத்தியம்	1	குறையவில்லை	1	சுலபமாக போக முடியும்
2	நாட்டு வைத்தியம்	2	சிறிது குறைந்தது	2	குணமாகுமென்ற நம்பிக்கை
3	மருந்து கடை	3	மோசமாகியது	3	எப்போதும் போகலாம்
4	ஆ.சு. நிலையம்	4	குணமடைந்தது, ஆனால் திரும்ப வந்தது	4	தனியார் மருத்துவர் அனுப்பினார்
5	தனியார் மருத்துவர்			5	இலவச சிகிழ்சை
6	அரசாங்க பொது மருத்துவமனை			6	பிறர் ஆலோசனைபடி
7	வேலூர் மருத்துவகல்லூரி			7	பிற
8	சாட் மருத்துவமனை				
9	கிறிஸ்தவ மருத்துவ கல்லூரி				
10	பிற				

35. அரசு ஆஸ்பத்திரி அல்லது சிஎம்சி, சாட் செல்லாததின் காரணம் என்ன

- 1) தேவையில்லை என நினைத்தேன்
- 2) வெகுதூரம்
- 3) மிகுந்த நேரம் காத்திருக்க வேண்டும்
- 4) இதற்கு முன் மோசமான அனுபவம்
- 5) பணமில்லை
- 6) பிற

36. நோய் அறிகுறி ஆரம்பித்து ஆஸ்பத்திரி செல்ல எவ்வளவு நாட்கள் ஆனது

37. இவ்வளவு நாள் ஆனதை காலதாமதம் என நினைக்கிறீர்களா

- 1) இல்லை
- 2) ஆம்

38. கேள்வி 34க்கு ஆம் என்றால் காலதாமதம் ஆகிறதற்கான காரணங்கள் யாது

குறி எண்	காரணங்கள்	குறி எண்	காரணங்கள்
1	என்ன நோய் என்று சொல்வார்களோ என்ற பயம்	5	ஊழியரின் மனபாங்கு /போக்கு சரியில்லை
2	தானாகவே சரியாகிவிடும் என்ற நம்பிக்கை	6	தரகுறைவான ஆஸ்பத்திரி
3	சமுதாயம் ஒதுக்கிவிடுமோ என்ற பயம்	7	பிற
4	பணக்கஷ்டம்	8	

39. உங்களுக்கு மபி பாதிப்பு கண்டறிந்த இடத்தில், என்ன சிகிழ்ச்சை கொடுக்கப்பட்டது

- 1) மருந்து கொடுத்து திரும்பி வர கூறினர்
- 2) சளி பரிசோதனை
- 3) இரத்த பரிசோதனை
- 4) எக்ஸ்ரே
- 5) பிற

40. சளி பரிசோதனை கொடுத்த நாள்

41. சளி முடிவு தெரிந்த நாள்

42. மருந்து ஆரம்பித்த நாள்

43. உங்களுக்கு வேறு இடத்தில் மருந்து ஆரம்பித்த பின் இங்கு அனுப்பி இருந்தால், எத்தனை நாட்களுக்கு பின் மருந்து தொடர கொடுக்கப்பட்டது

44. உங்கள் வீட்டிற்கும் ஆஸ்பத்திரிக்கும் எவ்வளவு தூரம்

45. உங்களை போன்ற உடலு பாதிப்பு இருக்கும் சிலர் சிகிழ்ச்சைக்கு போவதில்லை. அதற்கான காரணம் யாது

- 1) தேவையில்லை என நினைத்தேன்
- 2) வெகுதூரம்
- 3) மிகுந்த நேரம் காத்திருக்க வேண்டும்
- 4) இதற்கு முன் மோசமான அனுபவம்
- 5) பணமில்லை
- 6) பிற

46. நீங்கள் நோய் அறிகுறிக்கு பின்னர், நோய் கண்டறிந்த நாள் வரை, நோயின் பாதிப்பால் எத்தனை நாட்கள் வேலைக்கு போகவில்லை

### டீபி நோய் குறித்து அறிவு

47. உங்களுக்கு 2 வாரத்திற்கு மேல் இருமல் அல்லது ஜீரம் அல்லது எடை குறைவு அல்லது பசியின்மையினால் அவதி பட்ட போது, உங்களுக்கு டீபி நோய் பாதிப்பு இருக்கலாமென எப்போதாவது யோசித்தீர்களா

- 1) இல்லை 2) ஆம்

48. உங்களுக்கு டீபி நோய் கண்டறியுமுன் டீபி குறித்து கேள்விப் பட்டிருக்கிறீர்களா

- 1) இல்லை 2) ஆம்

49. உங்கள் கருத்துப்படி, டீபி பாதிப்பு எவ்வளவு ஆபத்தானது என நினைக்கிறீர்கள்

- 1) மிகவும் ஆபத்தானது 2) சுமாராக ஆபத்தானது 3) ஆபத்தானது இல்லை  
4) தெரியவில்லை

50. உங்கள் கருத்துப்படி, உங்கள் சமுதாயத்தில் டீபி பாதிப்பு எவ்வளவு ஆபத்தானது என நினைக்கிறீர்கள்

- 1) மிகவும் ஆபத்தானது 2) சுமாராக ஆபத்தானது 3) ஆபத்தானது இல்லை  
4) தெரியவில்லை

51. டீபி நோயின் அறிகுறிகள் யாவை

எண்	குறி	அறிகுறி	எண்	குறி	அறிகுறி
1	இருமல்		7	மாலைபொழுது/ இரவு ஜீரம்	
2	2 வாரத்திற்கு மேலாக இருமல்		8	மார்பு வலி	
3	இருமலில் இரத்தம்		9	மூச்சு கஷ்டம்	
4	சளியுடன்கூடிய இருமல்		10	தொடர்ந்து சோர்பு	
5	இடை குறைவாகிறது		11	பசியின்மை	
6	ஜீரம்		12	தெரியவில்லை	

52. எந்தெந்த முறையில் டீபி நோய் ஒருவருக்கு வரலாம்

- 1) கை குலுக்குவதால்
- 2) டீபியினால் பாதிக்கப்பட்டவர் இருமல்/தும்மும் போது, காற்றின் மூலம்
- 3) சாப்பாடு பகிரிந்து கொள்வது, ஓரே பாத்திரம்/கப்பில்
- 4) டீபியினால் பாதிக்கப்பட்டவர் தொட்டைத் தொடுவதினால்
- 5) டீபியினால் பாதிக்கப்பட்டவர் அருகாமையில் அமருவதால்
- 6) பரம்பரையாக வரும்
- 7) பொற்று நோய்
- 8) பிற

53. டீபி நோய் ஒருவருக்கு வராமல் எந்தெந்த முறையில் தடுக்கலாம்

- 1) கை குலுக்குவதை தடுப்பதால்
- 2) இருமும் போது/ தும்மும் போது வாயை/மூக்கை மூடுவதால்
- 3) சாப்பாடு பகிரிந்து கொள்வதை தவிர்ப்பதால்
- 4) பொது இடங்களில் உள்ள பொருட்களை தொட்டால் கையை கழுவுதல்
- 5) நன்கு காற்றோட்டமாக ஜன்னல்களை திறந்து வைப்பது
- 6) சத்தான உணவு உட்கொள்வது
- 7) ஜெபிப்பது
- 8) பிற
- 9) தெரியாது

54. உங்கள் கருத்துப்படி, டீபி பாதிப்பு யாருக்கு ஏற்படலாம்

- 1) யாருக்காகிலும்
- 2) ஏழைகளுக்கு
- 3) வீடில்லாதவர்களுக்கு
- 4) குடிப்பவர்களுக்கு
- 5) ஹெச்ஐவி/எயிட்ஸ் பாதிக்கப்பட்டவர்களுக்கு
- 6) சர்க்கரை நோயினால் பாதிக்கப்பட்டவர்களுக்கு
- 7) பிற
- 8) தெரியாது

55. டீபியை குணப்படுத்த முடியுமா 1) இல்லை 2) ஆம்

56. டீபி பாதிப்புக்கு உள்ளான ஒருவரை எவ்வாறு குணப்படுத்த முடியும்

- 1) மூலிகை மருந்து
- 2) ஜெபிப்பது
- 3) ஓய்வு எடுத்தால் (மருந்து தேவையில்லை)
- 4) மருத்துவர் அறிவுரைபடி மருந்து விடாமல் எடுப்பது
- 5) மற்றவர் கண்காணிப்பில் மருந்து உட்கொள்வது
- 6) சரியான உணவு உட்கொள்வது
- 7) பிற
- 8) தெரியாது

57. உத்தேசமாக எவ்வளவு காலம் மருந்து உட்கொள்ள வேண்டும்

58. சிகிழ்சை ஆரம்பித்த பின்னர், சளி பரிசோதனை செய்து கொள்ள வேண்டுமா

- 1) 1) இல்லை 2) ஆம் 3) தெரியாது

59. கேள்வி 57க்கு ஆம் என்றால், எத்தனை முறை

60. கேள்வி 57க்கு ஆம் என்றால், எத்தனை மாதத்திற்கு பின்னர்

## டீபியால் பாதிக்கப் பட்டவர் கருத்து

டீபி நோய் குறித்த சமுதாயத்தின் எண்ணம் குறித்து டீபியால் பாதிக்கப் பட்டவர் கருத்து

		மிகவும் ஒத்திக் கொள்ள மாட்டேன்	ஒத்திக் கொள்ள மாட்டேன்	ஒத்திக் கொள்கிறேன்	மிகவும் ஒத்திக் கொள்கிறேன்
1	டீபியால் பாதிக்கப்பட்டவர் நம் சமுதாயத்தில் இருப்பதை சிலர் விரும்ப மாட்டார்கள்				
2	சிலர் டீபியால் பாதிக்கப் பட்டவர்களை விட்டு அகன்று இருப்பார்கள்				
3	சிலர் டீபியால் பாதிக்கப் பட்டவர்களை விரும்பத் தகாதவர் என நினைக்கிறார்கள்				
4	சிலர் டீபியால் பாதிக்கப் பட்டவர்கள் அருகாமையில் இருப்பதை சிரமமாக நினைக்கிறார்கள்				
5	சிலர் டீபியால் பாதிக்கப் பட்டவர்களோடு தங்கள் குழந்தைகள் விளையாடுவதை விரும்பமாட்டார்கள்				
6	சிலர் டீபியால் பாதிக்கப் பட்டவர்களிடம் பேச விரும்பமாட்டார்கள்				
7	ஒருவருக்கு டீபி பாதிப்பு ஏற்பட்டால் அவர்களோடு சிலர் வாழ்நாள் முழுவதும் வித்தியாசமாக நடந்து கொள்வார்கள்				
8	சிலர் தங்கள் நண்பர்களுக்கு டீபி பாதிப்பு ஏற்பட்டால் அவர்களோடு சாப்பிடுவது அல்லது பானம் அருந்துவதை விரும்பமாட்டார்கள்				
9	சிலர் டீபியால் பாதிக்கப் பட்டவர்களை தொடுவதை தவிர்ப்பார்கள்				
10	சிலர் தங்கள் உறவினர்களுக்கு டீபி பாதிப்பு ஏற்பட்டால் அவர்களோடு சாப்பிடுவது அல்லது பானம் அருந்துவதை விரும்பமாட்டார்கள்				
11	சிலர் டீபியால் பாதிக்கப் பட்டவர்களுக்கு பயப்படுவார்கள்				



டீபி நோய் குறித்து நோயினால் பாதிக்க பட்டவரின் எண்ணம் குறித்து டீபியால் பாதிக்கப் பட்டவர் கருத்து

		மிகவும் ஒத்துக் கொள்ள மாட்டேன்	ஒத்துக் கொள்ள மாட்டேன்	ஒத்துக் கொள்கிறேன்	மிகவும் ஒத்துக் கொள்கிறேன்
1	டீபியால் பாதிக்கப்பட்டுள்ள சிலர் அவர்களை குடும்பத்தினர் கவனிப்பதின் மூலம் அவர்களுக்கு பாரமாக இருப்பதாக நினைத்து குற்ற உணர்வுள்ளவர்களாக இருக்கிறார்கள்				
2	டீபியால் பாதிக்கப்பட்டுள்ள சிலர் மற்றவர்களுக்கு கிருமி பரவாமல் இருக்கும் படி ஒதுங்கி இருப்பார்கள்				
3	டீபியால் பாதிக்கப்பட்டுள்ள சிலர் தனிமையை உணர்கிறார்கள்				
4	டீபியால் பாதிக்கப்பட்டுள்ள சிலர் பிறர் நமக்கு டீ பி நம்மிடம் நடந்து கொள்ளும் முறையினால் மனதில் புண படுகிறார்கள்				
5	டீபியால் பாதிக்கப்பட்டுள்ள சிலர் டீ பி இருப்பதை நண்பர்களிடம் கூறும் போது நண்பர்களை இழந்து விடுகிறார்கள்				
6	டீபியால் பாதிக்கப்பட்டுள்ள சிலர் தங்களுக்கு எயிட்ஸ் நோய் தாக்குதல் இருக்குமா என கவலை படுகிறார்கள்				
7	டீபியால் பாதிக்கப்பட்டுள்ள சிலர், குடும்பத்தினரை தவிர மற்றவர்களிடம் தனக்கு இந்த பாதிப்பு இருப்பதை கூற பயப்படுகிறார்கள்				
8	டீபியால் பாதிக்கப்பட்டுள்ள சிலர், பாதிப்பை யாரிடம் கூறலாம் என்பதை கவனமாக தெரிந்தெடுப்பார்கள்				
9	டீபியால் பாதிக்கப்பட்டுள்ள சிலர், பிறர் பார்த்துவிடுவார்கள் என நினைத்து டீ பி ஆஸ்பத்தரிக்கு போக				
10	டீபியால் பாதிக்கப்பட்டுள்ள சிலர், உறவினர்களிடம் தங்களுக்கு டீ பி பாதிப்பு இருப்பதை கூற தயங்குகிறார்கள்				
11	டீபியால் பாதிக்கப்பட்டுள்ள சிலர், பிறரிடம் தங்களுக்கு டீபி பாதிப்பு இருப்பதை கூறினால் தங்களுக்கு எயிட்ஸ் நோய் தாக்குதல் இருக்குமா என சந்தேகப் படுவார்களென தயங்குகிறார்கள்				
12	டீபியால் பாதிக்கப்பட்டுள்ள சிலர், தங்களது புகைபழக்கம்/ குடிபழக்கம்/ தங்களது கவனக்குறைவான நடத்தையினால் டீபி பாதிப்பு ஏற்பட்டிருக்குமென்ற குற்றமணப் பார்வையில் இருப்பார்கள்				

டீ பி யால் பாதிக்கப்பட்டுள்ள நபருக்கு ஏற்பட்ட நிந்தை அவருக்கு எவ்வாறு பாதிப்பு ஏற்படுத்தியுள்ளனது

## சமுதாய மக்களின் கருத்து

சமுதாயத்தின் கருத்து – டீபி நோய் குறித்து சமுதாயத்தின் எண்ணம்

		மிகவும் ஒத்துக் கொள்ள மாட்டேன்	ஒத்துக் கொள்ள மாட்டேன்	ஒத்துக் கொள்கிறேன்	மிகவும் ஒத்துக் கொள்கிறேன்
1	டீபியால் பாதிக்கப்பட்டவர் நம் சமுதாயத்தில் இருப்பதை சிலர் விரும்ப மாட்டார்கள்				
2	சிலர் டீபியால் பாதிக்கப் பட்டவர்களை விட்டு அகன்று இருப்பார்கள்				
3	சிலர் டீபியால் பாதிக்கப் பட்டவர்களை விரும்பத் தகாதவர் என நினைக்கிறார்கள்				
4	சிலர் டீபியால் பாதிக்கப் பட்டவர்கள் அருகாமையில் இருப்பதை சிரமமாக நினைக்கிறார்கள்				
5	சிலர் டீபியால் பாதிக்கப் பட்டவர்களோடு தங்கள் குழந்தைகள் விளையாடுவதை விரும்பமாட்டார்கள்				
6	சிலர் டீபியால் பாதிக்கப் பட்டவர்களிடம் பேச விரும்பமாட்டார்கள்				
7	ஒருவருக்கு டீபி பாதிப்பு ஏற்பட்டால் அவர்களோடு சிலர் வாழ்நாள் முழுவதும் வித்தியாசமாக நடந்து கொள்வார்கள்				
8	சிலர் தங்கள் நண்பர்களுக்கு டீபி பாதிப்பு ஏற்பட்டால் அவர்களோடு சாப்பிடுவது அல்லது பானம் அருந்துவதை விரும்பமாட்டார்கள்				
9	சிலர் டீபியால் பாதிக்கப் பட்டவர்களை தொடுவதை தவிர்ப்பார்கள்				
10	சிலர் தங்கள் உறவினர்களுக்கு டீபி பாதிப்பு ஏற்பட்டால் அவர்களோடு சாப்பிடுவது அல்லது பானம் அருந்துவதை விரும்பமாட்டார்கள்				
11	சிலர் டீபியால் பாதிக்கப் பட்டவர்களுக்கு பயப்படுவார்கள்				



சமுதாயத்தின் கருத்து - டீபி நோய் குறித்து நோயினால் பாதிக்க பட்டவரின் எண்ணம் குறித்து

		மிகவும் ஒத்துக் கொள்ள மாட்டேன்	ஒத்துக் கொள்ள மாட்டேன்	ஒத்துக் கொள்கிறேன்	மிகவும் ஒத்துக் கொள்கிறேன்
1	டீபியால் பாதிக்கப்பட்டுள்ள சிலர் அவர்களை குடும்பத்தினர் கவனிப்பதின் மூலம் அவர்களுக்கு பாரமாக இருப்பதாக நினைத்து குற்ற உணர்வுள்ளவர்களாக இருக்கிறார்கள்				
2	டீபியால் பாதிக்கப்பட்டுள்ள சிலர் மற்றவர்களுக்கு கிருமி பரவாமல் இருக்கும் படி ஒதுங்கி இருப்பார்கள்				
3	டீபியால் பாதிக்கப்பட்டுள்ள சிலர் தனிமையை உணர்கிறார்கள்				
4	டீபியால் பாதிக்கப்பட்டுள்ள சிலர் பிறர் நமக்கு டீ பி நம்மிடம் நடந்து கொள்ளும் முறையினால் மனதில் புண் படுகிறார்கள்				
5	டீபியால் பாதிக்கப்பட்டுள்ள சிலர் டீ பி இருப்பதை நண்பர்களிடம் கூறும் போது நண்பர்களை இழந்து விடுகிறார்கள்				
6	டீபியால் பாதிக்கப்பட்டுள்ள சிலர் தங்களுக்கு எயிட்ஸ் நோய் தாக்குதல் இருக்குமா என கவலை படுகிறார்கள்				
7	டீபியால் பாதிக்கப்பட்டுள்ள சிலர், குடும்பத்தினரை தவிர மற்றவர்களிடம் தனக்கு இந்த பாதிப்பு இருப்பதை கூற பயப்படுகிறார்கள்				
8	டீபியால் பாதிக்கப்பட்டுள்ள சிலர், பாதிப்பை யாரிடம் கூறலாம் என்பதை கவனமாக தெரிந்தெடுப்பார்கள்				
9	டீபியால் பாதிக்கப்பட்டுள்ள சிலர், பிறர் பார்த்துவிடுவார்கள் என நினைத்து டீ பி ஆஸ்பத்தரிக்கு போக				
10	டீபியால் பாதிக்கப்பட்டுள்ள சிலர், உறவினர்களிடம் தங்களுக்கு டீ பி பாதிப்பு இருப்பதை கூற தயங்குகிறார்கள்				
11	டீபியால் பாதிக்கப்பட்டுள்ள சிலர், பிறரிடம் தங்களுக்கு டீபி பாதிப்பு இருப்பதை கூறினால் தங்களுக்கு எயிட்ஸ் நோய் தாக்குதல் இருக்குமா என சந்தேகப் படுவார்களென தயங்குகிறார்கள்				
12	டீபியால் பாதிக்கப்பட்டுள்ள சிலர், தங்களது புகைபழக்கம்/ குடிபழக்கம்/ தங்களது கவனக்குறைவான நடத்தையினால் டீபி பாதிப்பு ஏற்பட்டிருக்குமென்ற குற்றமணப் பார்வையில் இருப்பார்கள்				

டீ பி யால் பாதிக்கப்பட்டுள்ள நபருக்கு ஏற்பட்ட நிந்தை அவருக்கு எவ்வாறு பாதிப்பு ஏற்படுத்தியுள்ளது

## Annexure 4

நீங்கள் இதில் பங்கேற்பதால் எங்களுக்கு எந்த வித செலவும் ஏற்படாது.

இந்த ஆய்வில் நீங்கள் பங்கேற்பதால் நியாயமாக எதிர்பார்க்கப்படும் அசௌகரியங்கள், கஷ்டங்கள் (மற்றும்) ஆபத்து காரணிகளின் விபரம்.

கேட்கப்படும் கேள்விகள் தங்களுக்கு எந்த ஒரு அசௌகரியத்தையும் ஏற்படுத்தாது ஏனெனில் அவை தங்கள் பிரச்சனையை கண்டறிவதில் உள்ள தாமதத்தையும் அதற்கு சிகிச்சை அளிப்பதில் உள்ள பிரச்சனைகளை புரிந்து கொள்வதற்காக மட்டும்.

அசௌகரியத்தை தவிர்க்க, தங்களுக்கு வசதியான இடத்தில் அல்லது க்ளினிக்கோ அல்லது வீட்டிற்கோ வந்து நான் சந்திப்பேன்.

**முன்கூட்டியே எதிர்பார்க்கப்படாத ஆபத்துகள்**

தங்களை சந்திப்பதற்கான சரியான நேரம் இடம் மற்றும் தேவையான நடவடிக்கைகள் எடுக்கப்படுவதால் இதில் எந்த ஒரு ஆபத்தும் இல்லை.

**ஆய்வு சம்பந்தமான விபத்துக்களுக்கான நஷ்டஈடு**

இந்த ஆய்வு மூலமாக எந்த ஒரு விபத்தும் எதிர்பார்க்க கூடியதாக இல்லை. ஆதலால் எந்த ஒரு நஷ்டஈடும் தரப்படமாட்டாது.

**இந்த ஆய்வின் மூலம் எதிர்பார்க்கப்படும் பலன்கள்**

இந்த ஆய்வின் முக்கிய நோக்கமானது, இந்த நோய்க்கான உதவுதலில் அரசாங்கத்தின் தலையீடு நல்லதாக இருந்தாலும் இந்த நோய் கண்டறிதலில் உள்ள தாமதம் மற்றும் பல்வேறு பிரச்சனைகளைகள் கண்டறிதலே ஆகும் இந்த மேற்காணலின்போது தேவைப்படும் தகவலை கண்டுபிடிப்பீர்கள்.

## ஒப்புதல் படிவம்

தென் இந்தியாவில் காசநோயால் பாதிக்கப்பட்ட மக்களுக்கு ஆரம்ப நிலையில் இந்நோயைக் கண்டறிதல் மற்றும் சிகைச்சை துவங்குவதில் ஏற்படும் தடைகளை பற்றிய ஆய்வு.

தேதி :

ஆய்வு எண் :

ஆய்வில் பங்கேற்பவரின் பெயர் :

ஆய்வில் பங்கேற்பவரின் (தாய் / கணவரின் பெயர் ) :

வயது : கிராமம்/நகரம் :

இந்த ஆய்வு கிராமங்களில் இருக்கும் மக்களுக்கு காசநோயை ஆரம்ப நிலையில் கண்டறிதல் மற்றும் சிகைச்சை துவங்குவதில் ஏற்படும் தாமதங்களை ஏற்படுத்தும் தடைகளை கண்டறிய நடத்தப்படுகிறது. இந்த ஆய்வின் முடிவுகள் சமூகத்திற்கு விழிப்புணர்வு ஏற்படுத்த பயன்படுத்தப்படும் என்று அறிந்திருக்கிறேன். சிகைச்சை ஆரம்பிப்பதில் ஏற்படும் தாமதங்களுக்கான காரணங்களை கண்டறிடத்து இதன்மூலம் நோய் பரவுவது குறைந்து ஆராய்ச்சியுமான சமுதாயம் உருவாக்க உதவும்.

இந்த ஆய்வில் எனது பங்கேற்பு தன்னிச்சையானது என்பதை புரிந்து கொண்டேன். இந்த ஆய்வில் நான் பங்கு கொள்ள விருப்பமில்லை என்றாலும் ஆய்வாளரின் நிறுவனத்தில் என்னுடைய (குடும்பம்) தற்போது மற்றும் எதிர்கால மருத்துவ பராமரிப்பு பாதிக்கபடாது என்று தகவல் படிவத்தை படித்து பார்த்து ஆய்வாளரால் படித்து காண்பிக்கப்பட்டு தெரிந்து கொண்டேன்.

என்னுடைய அடையாளம் மற்றும் என்னுடைய தகவல்கள் அனைத்தும் இரகசியம் காக்கப்பட்டு, இந்த ஆய்வின் நோக்கத்திற்காக மட்டுமே பயன்படுத்தப்படும் என்பதை நான் புரிந்துகொண்டேன். எப்படியாயினும் இந்த ஆய்வின் முடிவுகள் வெளியிடப்படலாம்.

நான் கொடுத்த தகவலை படிக்க ஆய்வாளருக்கும் மற்ற ஆராய்ச்சியாளருக்கும் என்னுடைய அனுமதி தற்போது அல்லது எதிர்கால ஆய்வின் போதும் தேவையில்லை என்பதற்கு நான் ஒப்புக்கொள்கிறேன். ஆனால் என்னுடைய அடையாளம் மூன்றாம் நபருக்கு வெளிப்படுத்தப்படாது மற்றும் ஆய்வின் வெளியிட்டிலும் வெளிப்படுத்தப்படாது.

இந்த ஆய்வை குறித்த தகவல்களை படித்து புரிந்துள்ளேன் அல்லது எனக்கு எனது மொழியில் படித்து காட்டப்பட்டது. நான் கேள்விகள் கேட்க வாய்ப்பு கொடுக்கப்பட்டது.

ஆய்வாளர் என்னை தொலைப்பேசியில் தொடர்பு கொள்ளவும் என்னை நேரிடையாக சந்தித்து நோயை குறித்து தகவல் கேட்க ஒப்புக் கொள்கிறேன்.

பங்கெடுப்பவரின் கையொப்பம்/கைவிரல்ரேகை :

தேதி :

சாட்சியாளரின் கையொப்பம்: 1.

2.

தேதி :

ஆய்வாளரின் கையொப்பம்:

தேதி :

ஆய்வை குறித்த கேள்விகள் இருப்பின் தொடர்பு கொள்ள வேண்டிய நபர்கள் :

நோயாளி தகவல் படிவம்

( 18 வயது (அ) மேற்பட்டவர்களுக்க பொருந்தும்)



## Annexure 5

### Questionnaire

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#### General Questionnaire:

1. Date of interview:
2. Study number:
3. Village name:
4. T.B registers no.
5. Name of the respondent
6. Age
7. Sex: 1. Male      2. Female
8. Number of household members
9. Number of rooms in the house
10. Education of the respondent:
11. Education of spouse/father:
12. Occupation of the respondent prior to illness:
13. Daily wage/salary prior to illness:
14. Occupation of the respondent currently:
15. Daily wage/salary currently:
16. Occupation (spouse/father):
17. Family income-pm (prior to illness):
18. Family income (current)-pm:
19. Type of house:      1. Hut      2. Thatched      3. Tiled      4. Terraced
20. Total debt due to medical expense
21. Residence:      1. Rural      2. Urban      3. Urban slum      4. Homeless
22. Marital status: 1. Single      2. Married      3. Divorced/separated      4. Widowed
23. History of smoking:      1. Never      2. Past smoking      3. Current smoking
24. If 2 or 3 to Q No 23, number cigarettes smoked/day:
25. Duration of smoking: years-----, months-----
26. History of alcohol use: 1. Never      2. Past user      3. Current user
27. If 2 or 3 to Q No 26, How frequently .....
28. If 2 or 3 to Q No 26, How much per week .....
29. Previous history of treatment for TB: 1. No      2. Yes (give details)
30. Family history of TB:      1. No      2. Yes (Give details)
31. Other chronic illness: 1. none      2. HIV      3. Diabetes      4. COPD      5. Bronchial asthma      6. Other (give details)

### **Treatment seeking behavior:**

32. Did you have any of the following symptoms? If yes, write the date of onset

Code No	Symptom	Date of onset	Duration in days
1	Cough		
2	Fever		
3	Loss of weight		
4	Loss of appetite		
5	Haemoptysis		
6	Chest pain		
7	Others (specify)		

33. Which of the above symptom made you seek health care?

34. Health seeking after onset of symptoms, but before initial diagnosis and cost of consultation:

Place code (in the order of sequence)	Date	Outcome of treatment	Reasons for choosing	Total medical expenditure

Code:

Place of treatment		Outcome		Reasons	
Code No	Health care provider	Code No	Outcome	Code No	Reasons
0	None	0	NA	0	NA
1	Self-medication	1	No improvement	1	Accessible
2	Traditional medicine	2	Slight improvement	2	Confidence in getting cured
3	Pharmacist/chemist shop	3	Worsened	3	Services available any time
4	PHC	4	Cured, but recurred	4	Referred by private health service
5	Private Doctor	5		5	Free services
6	GH/CHC			6	Recommended by someone
7	GVMC			7	Other
8	CHAD				
9	CMCH				
10	Other				

35. Reasons for non-consultation of health facility (PHC/GH/CHC/GVMC/CHAD/CMC) with the onset of symptoms

- |   |                     |
|---|---------------------|
| 1) Thought 'as not necessary'                 | 2) Too far          |
| 3) Too busy health facility/long waiting time | 4) Bad experience   |
| 5) No money                                   | 6) others (specify) |

36. How long did it take from the time you first feel sick and the time you went to health facility?

37. Do you consider this time as a delay? 1. No 2. Yes

38. If yes to Q No 37, according to you, what are the causes of delay in your health seeking behavior?

1	Fear of what would be found on diagnosis	5	Unsatisfying staff attitude
2	Hopped their symptoms would go away on their own	6	Poor quality of health services
3	Fear of social isolation	7	Others (specify)
4	Economic constraints		

39. In the centre where you have been diagnosed, what did they do? (multiple options can be ticked)

- 1) Gave medicines and review
- 2) Sputum testing
- 3) Blood testing
- 4) X-ray
- 5) Other (specify)

40. Date of testing sputum:

41. Date of diagnosis:

42. Date of initiation of treatment:

43. If you have been transferred from some other place to this centre, after how many days you have been started on regular treatment?

44. Distance from your house to the nearest health facility?

45. Some people do not seek health care when they have the same condition as you have. What do you think, the causes would be?

- |   |                     |
|---|---------------------|
| 1) Think it is unnecessary                    | 2) Too far          |
| 3) Too busy health facility/long waiting time | 4) Bad experience   |
| 5) No money                                   | 6) Others (specify) |

46. How many days you could not go to work due to your illness (from the time of onset of symptom till starting treatment)

### Knowledge questionnaire on T.B

---

47. When you suffered from cough or fever or decreased weight and loss of appetite for more than 2 weeks have you ever thought that you might be suffering from T.B?

- 1) No 2) Yes

48. Before you were diagnosed with TB, have you ever heard about TB?

- 1) No 2) Yes

49. In your opinion, how serious is tuberculosis? [Read the options and mark one answer only]

- 1) Very serious
- 2) Somewhat serious
- 3) Not that serious
- 4) Not sure

50. How serious do you consider the issue of T.B. in your community? [Read the options and mark one answer only]

- 1) Very serious
- 2) Somewhat serious
- 3) Not that serious
- 4) Not sure

51. What are the signs and symptoms of tuberculosis?

1	Cough	7	Evening or night fever
2	Cough lasting more than 2 weeks	8	Chest pain
3	Cough with blood	9	Short of breath
4	Cough with phlegm	10	Constant fatigue
5	Loss of weight	11	Loss of appetite
6	Fever	12	Not sure

52. In which ways, can someone get tuberculosis? (Unprompted, multiple options possible)

- 1) By a hand shake
- 2) Through air, when somebody with T.B coughs /sneezes
- 3) Sharing meals, using same plate/cups
- 4) Touching something a person with TB has touched
- 5) Sitting next to someone with TB
- 6) Hereditary
- 7) Contagious disease
- 8) Others (specify)



53. How can a person prevent from getting this disease? (Unprompted, multiple options possible)

- 1) Avoiding hand shakes
- 2) Covering your mouth or nose while coughing
- 3) Avoid sharing meals
- 4) Washing your hands after touching something in public places
- 5) Opening the windows, having good ventilation
- 6) Having good nutrition
- 7) Praying
- 8) Others
- 9) Do not know

54. In your opinion who can get tuberculosis? (Unprompted, multiple options possible)

- |                         |                         |
|-------------------------|-------------------------|
| 1) Anyone               | 2) Poor people          |
| 3) Homeless people      | 4) Alcoholics           |
| 5) People with HIV/AIDS | 6) People with diabetes |
| 7) Others               | 8) Don't know           |

55. Can TB be cured?    1. No                      2. Yes                      3. Don't know

56. How can a person suffering from TB be cured? (Unprompted, multiple options possible)

- 1) Herbs medicines
- 2) Praying
- 3) Resting at home without taking any medicine
- 4) Taking Medication regularly as prescribed by a doctor or a health center
- 5) Tuberculosis medication administered/ supervised by DOTS provider
- 6) Taking proper diet
- 7) Others
- 8) Don't know

57. What is the approximate duration of treatment?

58. Are you expected to check your sputum sometimes after starting treatment?

- 1) No                      2) Yes                      3) Don't know

59. If yes to Q No 58, how many times?

60. If yes to Q No 58, how many months after starting treatment?

## QUESTIONNAIRE ON TUBERCULOSIS RELATED STIGMA

### A. Community perspective towards tuberculosis (from person with TB)

		Strongly disagree	Disagree	Agree	Strongly agree
1	Some people may not want to eat or drink with friends who have T.B				
2	Some people feel uncomfortable about being near those with T.B				
3	If a person has T.B, some community members will behave differently towards that person for the rest of his/her life				
4	Some people do not want those with TB playing with their children				
5	Some people keep their distance from people with TB				
6	Some people think that those with TB are disgusting				
7	Some people do not to talk with others about TB				
8	Some people are afraid of those with TB				
9	Some people try not to touch others with TB				
10	Some people may not want to eat or drink with relatives who have TB				
11	Some people not to have those with TB live in their community				

### B. Patient perspectives towards tuberculosis (from person with TB)

		Strongly disagree	Disagree	Agree	Strongly agree
1	Some people who have TB feel hurt of how others react to knowing they have TB				
2	Some people who have TB lose friends when they share with them they have TB				
3	Some people who have TB feel alone				
4	Some people who have TB keep their distance from others to avoid spreading TB germs				
5	Some people who have TB are afraid to tell those outside their family that they have TB				
6	Some people who have TB are afraid of going to TB clinics because other people may see them there				
7	Some people who have TB are afraid to tell others that they have TB because others may think that they also have AIDS				
8	Some people who have TB feel guilty because their family has the burden of caring for them				
9	Some people who have TB Some people who have TB will choose carefully who they tell about having TB				
10	Some people who have TB feel guilty for getting TB because of their smoking, drinking, or other careless behavior s				
11	Some people who have TB are worried about having AIDS				
12	Some people who have TB are afraid to tell their family that they have TB				

How can stigma affect a person with TB in a negative way? (*Write literally*)

## Community's perception:

### A. Community perspective towards tuberculosis (from community member)


		Strongly disagree	Disagree	Agree	Strongly agree
1	Some people may not want to eat or drink with friends who have T.B				
2	Some people feel uncomfortable about being near those with T.B				
3	If a person has T.B, some community members will behave differently towards that person for the rest of his/her life				
4	Some people do not want those with TB playing with their children				
5	Some people keep their distance from people with TB				
6	Some people think that those with TB are disgusting				
7	Some people do not to talk with others about TB				
8	Some people are afraid of those with TB				
9	Some people try not to touch others with TB				
10	Some people may not want to eat or drink with relatives who have TB				
11	Some people not to have those with TB live in their community				

### B. Patient perspectives towards tuberculosis (from community member)

		Strongly disagree	Disagree	Agree	Strongly agree
1	Some people who have TB feel hurt of how others react to knowing they have TB				
2	Some people who have TB lose friends when they share with them they have TB				
3	Some people who have TB feel alone				
4	Some people who have TB keep their distance from others to avoid spreading TB germs				
5	Some people who have TB are afraid to tell those outside their family that they have TB				
6	Some people who have TB are afraid of going to TB clinics because other people may see them there				
7	Some people who have TB are afraid to tell others that they have TB because others may think that they also have AIDS				
8	Some people who have TB feel guilty because their family has the burden of caring for them				
9	Some people who have TB Some people who have TB will choose carefully who they tell about having TB				
10	Some people who have TB feel guilty for getting TB because of their smoking, drinking, or other careless behaviors				
11	Some people who have TB are worried about having AIDS				
12	Some people who have TB are afraid to tell their family that they have TB				

How can stigma affect a person with TB in a negative way? (*Write literally*)

## Annexure 6



**OFFICE OF RESEARCH  
INSTITUTIONAL REVIEW BOARD (IRB)  
CHRISTIAN MEDICAL COLLEGE, VELLORE, INDIA.**

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**Dr. B.J. Prashantham, M.A., M.A., Dr. Min (Clinical)**  
Director, Christian Counseling Center,  
Chairperson, Ethics Committee.

**Dr. Alfred Job Daniel, D Ortho, MS Ortho, DNB Ortho**  
Chairperson, Research Committee & Principal

**Dr. Nihal Thomas,**  
MD., MNAMS., DNB (Endo), FRACP (Endo), FRCP (Edin), FRCP (Glasg)  
Deputy Chairperson  
Secretary, Ethics Committee, IRB  
Additional Vice Principal (Research)

January 03, 2015

Dr. Harika Siddabathula  
PG Registrar  
Department of Community Health  
Christian Medical College, Vellore 632 002

Sub: **Fluid Research Grant Project:**  
Factors affecting health seeking behaviour associated with delay in early diagnosis and initiation of treatment for tuberculosis in Southern India.  
Dr. Harika Siddabathula, Dr. Jasmine Helan Prasad, Dr. Manjunath, Community Health, Dr. D. J. Christopher, Pulmonary Medicine, CMC, Vellore.

Ref: IRB Min No: 9129 [OBSERVE] dated 12.11.2014


Dear Dr. Harika Siddabathula,

I enclose the following documents:-

1. Institutional Review Board approval
2. Agreement

Could you please sign the agreement and send it to Dr. Nihal Thomas, Addl. Vice Principal (Research), so that the grant money can be released.

With best wishes,



**Dr. Nihal Thomas**  
Secretary (Ethics Committee)  
Institutional Review Board

MD, MNAMS, DNB (Endo), FRACP (Endo), FRCP (Edin), FRCP (Glasg)  
SECRETARY - (ETHICS COMMITTEE)  
Institutional Review Board,  
Christian Medical College, Vellore - 632 002.

Cc: Dr. Jasmine Helan Prasad, Community Health, CMC, Vellore.

1 of 5



**OFFICE OF RESEARCH  
INSTITUTIONAL REVIEW BOARD (IRB)  
CHRISTIAN MEDICAL COLLEGE, VELLORE, INDIA.**

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Ref: IRB Min No: 9129 [OBSERVE] dated 12.11.2014

Dear Dr. Harika Siddabathula,

The Institutional Review Board (Blue, Research and Ethics Committee) of the Christian Medical College, Vellore, reviewed and discussed your project entitled "Factors affecting health seeking behaviour associated with delay in early diagnosis and initiation of treatment for tuberculosis in Southern India." on November 12<sup>th</sup> 2014.

The Committees reviewed the following documents:

1. IRB Application format
2. Curriculum Vitae of Drs. Harika Siddabathula, Jasmine Helan Prasad, Manjunath, D. J. Christopher.
3. Informed Consent form (English & Tamil)
4. Information Sheet (English & Tamil)
5. No of documents 1-4

The following Institutional Review Board (Blue, Research & Ethics Committee) members were present at the meeting held on November 12<sup>th</sup> 2014 in the CREST/SACN Conference Room, Christian Medical College, Bagayam, Vellore 632002.

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